

Anticipating the Awakening: The Lived Experience of Families of Patients Undergoing  
Successful Targeted Temperature Management After Cardiac Arrest

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## Table of Contents

List of Tables.....	iv
Abstract.....	v
Acknowledgements.....	vi
CHAPTER 1 Background.....	1
Purpose.....	3
Research Question.....	3
Relevance to Nursing.....	4
Phenomenological Perspective.....	5
Summary.....	5
CHAPTER 2 Review of Literature and Nursing Perspective.....	7
The Family Members' Experience of Loved One's Cardiac Arrest.....	7
Families' Experience of the Intensive Care Unit and Critical Illness.....	11
Nursing Care of the Family of the Critically Ill Patient.....	15
The Family Members' Experience of Targeted Temperature Management.....	16
Nursing Perspective.....	21
Researcher's Presuppositions.....	21
Summary.....	23
CHAPTER 3 Method.....	25
Giorgi's Phenomenological Psychological Approach.....	25
Participants.....	26
Pilot Study.....	30
Data Collection.....	30

Setting.....	31
Data Analysis.....	31
Ethical Considerations.....	32
Trustworthiness.....	34
Dissemination of Results.....	36
Summary.....	37
CHAPTER 4 Research Findings.....	38
Description of Participants.....	38
Phenomenological Psychological Analysis of Results.....	40
Typology of the Lived Experience of Families of Patients Undergoing Successful Targeted Temperature Management After Cardiac Arrest.....	40
Summary.....	60
CHAPTER 5 Discussion.....	62
Summary.....	79
CHAPTER 6 Researcher’s Journey, Limitations, and Implications.....	81
Researcher’s Journey .....	81
Limitations.....	82
Implications.....	83
Implications for Practice.....	84
Implications for Theory.....	86
Implications for Education.....	87
Recommendations for Future Research.....	88

Conclusion.....	89
References.....	91
Appendices	
A. Letters of Permission from Health Prince Edward Island.....	101
B. A Script for Use by the ICU Nurse Manager During Recruitment.....	105
C. Participant’s Letter of Invitation.....	106
D. Written Consent Form for the Study.....	108
E. Interview Guide and Demographic Data.....	110
F. UPEI Research Ethics Board Approval.....	112
G. Health PEI Research Ethics Board Approval.....	113

## **List of Tables**

Table 1	Demographics of Participants.....	39
Table 2	A Typology of the Lived Experience of Families of Patients Undergoing Successful Targeted Temperature Management After Cardiac Arrest.....	41

## Abstract

Targeted temperature management (TTM), formally known as therapeutic hypothermia, is a relatively novel treatment that increases survival and neurological recovery after cardiac arrest. Survivors of successful TTM after cardiac arrest have no memory of the event or of their time in the Intensive Care Unit (ICU); this is in stark contrast to the families' experience of this event. To date, few studies have attempted to describe the families' experience of their loved ones' successful treatment with TTM. Findings from previous studies into this phenomenon reveal the families' experience to be one of pain, hope, hopelessness, and anxiety. The aim of this study was to describe further the lived experience of families of patients who have undergone successful TTM. A descriptive phenomenological inquiry was conducted using a purposive and snowball sampling strategy to recruit nine participants to ensure data saturation was reached. Participants were invited to participate if they were at least 18 years of age or older, able to read and speak English, and previously had an immediate family member receive TTM after cardiac arrest. Data were collected through digitally audio-taped, one-on-one interviews, using a semi-structured interview guide. Giorgi's (2009) descriptive phenomenological psychological method of analysis was used to form a description of the meaning of the experience as lived by families. New knowledge was revealed regarding the structure of the families' experience. The constituents include: the provocation of existential challenges felt by family members, differences in perceived realities that were dependent upon family roles, and the additional burden that family members experienced when their loved one was transferred to another health centre a significant distance away for ongoing treatment after TTM. This new knowledge further enhances nurses' understanding about the family member's experience of a loved one's successful TTM, thereby enabling them to better meet the health needs of these individuals.

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are. Because of their willingness to share these very private and personal experiences, I hope that we as nurses can better care for these families in the future.



## **CHAPTER 1**

### **Background**

Cardiac arrest affects up to 40,000 Canadians each year (Heart & Stroke, 2017). Of the cardiac arrests that occur outside of the hospital, 70.1% of them occur in the home (Vellano, Crouch, Rajdev, & McNally, 2015). Patient outcomes after cardiac arrest are relatively poor because of neurological sequelae (Larsson, Wallin, Rubertsson, & Kristoferzon, 2013), and survival rates of 3-9% have been reported (Bernard, 1998). The global cerebral ischemia that is associated with cardiac arrest frequently results in neurological damage (Holzer et al., 2002). Laver, Farrow, Turner, and Nolan (2004) found that of those patients who died in the intensive care unit (ICU) after an out-of-hospital cardiac arrest, two-thirds died due to neurological injury. A significant advance in the treatment of patients who are resuscitated from cardiac arrest, but remain comatose, is the neuroprotective strategy of therapeutic hypothermia (TH) (Silva & Frontera, 2013). Therapeutic hypothermia after cardiac arrest has been shown to improve neurological function and reduce mortality (Bernard et al., 2002; Holzer et al., 2002). Therapeutic hypothermia involves reducing the patient's core temperature to between 32°C-34°C for 24 hours (Holzer et al., 2002). Recently, the recommendation for this temperature range has changed to be between 32°C-36°C, and instead of being referred to as TH, the intervention is now referred to as targeted temperature management (TTM) (Callaway et al., 2015).

The Cardiac Arrest Registry to Enhance Survival (CARES) in the United States found that 36.4% of patients who are resuscitated from cardiac arrest and treated with TTM will survive to hospital discharge (CARES, 2016). Study results at a Canadian centre found that 55% of patients who were treated with TTM after cardiac arrest survived to hospital discharge (MacLean, Stevenson, Bata, & Green, 2012). At a Canadian tertiary care centre, the Intensive

Care Unit (ICU) typically provides TTM to eight survivors of cardiac arrest each year. Local experience reveals that when patients are treated with TTM, 50% will survive to hospital discharge neurologically intact, whereas the remaining 50% die while in hospital (Burns, 2012). TTM is recommended for all cardiac arrest survivors who remain comatose after restoration of spontaneous circulation (Callaway et al., 2015). Initiation and maintenance of a core temperature between 32°C-36°C requires that the patient be intubated and mechanically ventilated. Additionally, the patient is continuously administered an intravenous sedative and neuromuscular blocking agents, which achieve chemical paralysis so that the patient will not shiver at the reduced core temperature (Noyes & Lundbye, 2015). The result of these interventions is that the patient appears still and cool to touch while being mechanically ventilated. The patient's prognosis is uncertain during treatment with TTM and remains so for at least 72- 96 hours after the event (Taccone et al., 2014). Because of these difficulties with prognostication, patients and families may endure prolonged ICU admissions before a diagnosis of severe neurological injury is identified; this can be devastating for families (Stub, Bernard, Duffy, & Kaye, 2011).

The families' experience of the phenomenon of a loved one's cardiac arrest and subsequent treatment with TTM has received little attention in the nursing and health care literature (Holm, Norekval, Falun, & Gjengedal, 2012; Larsson et al., 2013; Löf, Sandström, & Engström Å, 2010). Löf et al. describe families of patients undergoing TTM as being in a unique situation as this sudden, unexpected event brings their lives to a halt. Family members describe the cardiac arrest as traumatic and frightening; the time during TTM is also difficult because of the significant inherent uncertainty about the future, and because their loved one appears lifeless, cold, and feels like he or she has died (Löf et al., 2010). If the patient survives to hospital

discharge, his or her partner describe feelings of anxiety and unexpected challenges in his or her everyday life after discharge (Holm et al., 2012). In one study, partners of patients who survived cardiac arrest and subsequent treatment with TTM were found to suffer from severe, negative consequences of the experience including sleep disturbances, difficulties relaxing, fears of recurrence, and permanent emotional distress (Wallin, Larsson, Rubertsson, & Kristoferzon, 2013). Of the limited amount of research that has been conducted on the families' experience of a loved one's cardiac arrest and treatment with TTM, only one study by Holm et al. focused on the partner's experience. This Scandinavian study utilized a phenomenological approach to describe the structure of a family member's experience of this phenomenon.

When compared to other critical illnesses, a patient's treatment with TTM is a unique experience; families find it unpleasant to see their loved one pale and cold to touch (Wallin et al., 2013). Although there has been a call for further research to develop interventions to support families of patients who receive TTM after cardiac arrest (Löf et al., 2010), this has, in reality, received little attention. To date, there has not been a phenomenological inquiry published that describes the lived experience of family members during successful treatment with TTM. This study aims to fill this gap in knowledge.

### **Purpose**

The purpose of this qualitative study is to explore the family's experience of a loved one's successful treatment with TTM.

### **Research Question**

This study aimed to reveal the structure of the lived experience of families of patients who received TTM after cardiac arrest. Therefore, the research question that guided this study was: What is the lived experience of families of patients who have undergone successful TTM

after cardiac arrest?

### **Relevance to Nursing**

There has been a paucity of research conducted that has sought to describe the lived experience of family members during successful treatment with TTM after a loved one's survival, with minimal neurological disability, after cardiac arrest. This identified gap in knowledge is significant to nursing; in particular, critical care nurses who care for both the patients and their families (Agård & Harder, 2007; Al-Mutair, Plummer, Clerehan, & O'Brien, 2014). Families experience acute, unique needs in the technical, unfamiliar environment of ICU, therefore critical care nurses are optimally placed to provide the type of specialized care that these families need. Critical care nurses act as a resource for families and can help families manage their anxiety and stress when their loved one is admitted to ICU (Titler, Bombei, & Schutte, 1995; Wong, Liamputtong, Koch, & Rawson, 2015). Although nurses are well positioned to care for the families of these patients, Wallin et al. (2013) found that family members of patients treated with TTM after cardiac arrest felt abandoned by health care professionals after their loved one was transferred out of ICU and then again when they were discharged from the hospital. Holm et al. (2012) went further to state that more studies are required to increase our knowledge of care of the family in highly technical environments so that nurses are better prepared to optimize their care of these individuals. Additionally, Löf et al. (2010) called for more research to be conducted so that appropriate support interventions are developed for family members of patients treated with TTM after cardiac arrest. Increasing our nursing knowledge of the family's experience of a loved one's successful treatment with TTM after cardiac arrest may lead to health care providers being better able to meet the family's needs (Löf et al., 2010).

## **Phenomenological Perspective**

In this study, I proposed to describe the essential structure of the family members' experience of the phenomenon of TTM after a loved one's successful survival from cardiac arrest. Families suffer from significant, long-term consequences after a loved one's cardiac arrest and treatment with TTM (Wallin et al., 2013). Giorgi's (2009) phenomenological psychological method aims to reveal the meaning of a phenomenon as experienced by a human being. Because of the adverse psychological consequences that result when families experience this phenomenon (Wallin et al., 2013), Giorgi's method is appropriate in meeting the purpose of this study. Utilization of this method for data analysis will increase the researcher's understanding of the family's lived experience of a loved one's successful treatment with TTM after cardiac arrest. This research will add to our current nursing knowledge about this phenomenon; a better understanding of the families' experience of this phenomenon is required before an intervention to support them can be designed and tested.

## **Summary**

The experience of a loved one's successful treatment with TTM after cardiac arrest may have significant adverse consequences for family members; however, this phenomenon has received little attention in the literature. In this chapter, I have outlined the relevant background information about the phenomenon of TTM after cardiac arrest, identified the gap in nursing knowledge, and stated the relevance of this gap to the nursing profession. To fill this gap in knowledge, an outline of the study is provided, describing how the utilization of Giorgi's (2009) phenomenological psychological method can deepen our understanding of the family members' lived experience of a loved one's successful treatment with TTM after cardiac arrest. It is my belief that the findings of this study will significantly contribute to existing nursing knowledge of

this phenomenon, and therefore will assist critical care nurses when caring for this patient population.

## **CHAPTER 2**

### **Review of Literature and Nursing Perspective**

In order to understand the phenomenon of TTM, it is important to review what previous information is found in the literature. Specifically, this exploration will review the family members' experience of a loved one's cardiac arrest, the family members' experience of ICU and critical illness, the nursing care of the critically ill patient, and the family member's experience of TTM. After this review, the nursing perspective and gap in nursing knowledge will be identified.

#### **The Family Member's Experience of a Loved One's Cardiac Arrest**

Family, as a concept, has gradually become more diverse with time (McKiernan & McCarthy, 2010). In the literature, a family has been defined as any individual who considers him or herself to be a member of the family (Leske, 2002). Wong et al. (2015) defined family as anyone who is related to the patient by blood, marriage, adoption, is considered to be part of the patient's support system, or who considers him or herself as a part of the family. Some research conducted on families of ICU patients has been more specific as to the definition of family. For example, McKiernan and McCarthy (2010) defined a family member as a spouse, parent, child, or any other person described as significant to the patient. Similarly, in their family-orientated, qualitative ICU research, Frivold, Dale, and Slettebø (2015) considered spouse, child, sibling, and grandchild to be close family members. In the ICU, the patient should be asked to define his or her family upon admission. However, if the patient is unable to communicate upon his or her admission to ICU, the ICU Registered Nurse (RN) should make the decision as to what constitutes the patient's family (Usher & Hill, 2016). Because a variety of definitions has been used to describe what constitutes a family, the researcher will operationalize the definition of

family in order to clarify whom the potential participants may be for the proposed study. For the purpose of this study, family will be defined as a partner, sibling, child, or parent.

The majority of patients who experience an out of hospital cardiac arrest suffer an unexpected and sudden death; only 23.8% of patients are resuscitated and survive to hospital admission (Bremer, Dahlberg, & Sandman, 2009; Sasson, Rogers, Dahl, & Kellermann, 2010). Significant others who are present for their loved one's cardiac arrest describe the situation as unexpected and dramatic; the normal pace of life suddenly accelerates into an unfolding disaster, both unreal and difficult to understand (Bremer et al., 2009; Larsson et al., 2013; Weslien, Nilstun, Lundqvist, & Fridlund, 2005). Their experience is described as traumatic where initial surprise swiftly turns into panic, shock, and fear when they realize that they are solely responsible for helping their loved one (Ann-Britt, Ella, Johan, & Åsa, 2010; Bremer et al., 2009; Holm et al., 2012). Weslien et al. found that fear of their loved one dying made it virtually impossible for a family member to initiate actions in response to the cardiac arrest. Partners described the experience of initiating cardiopulmonary resuscitation (CPR) as a time of chaos, fright, and loneliness (Holm et al., 2012). While waiting for paramedic staff to arrive, the significant other felt as if time had come to a standstill (Bremer et al., 2009; Larsson et al., 2013).

The resuscitation event itself has been described as a time when the significant other is caught between feeling hope and dread (Bremer et al., 2009). In one study, family members expressed relief, hope, and reduced stress when paramedics arrived. Moreover, they expected the paramedics to focus on the needs of their loved one and they actively tried to help the paramedics through the provision of relevant medical information about their loved one, or by attending to requests of the paramedics during the event (Weslien et al., 2005).

Weslien et al. (2005) also found that upon arrival to the hospital, family members



experienced relief when they saw their resuscitated loved one; others suspected a bad prognosis when listening to the healthcare provider's conversation and watching the cardiac monitor. This bad prognosis was then confirmed by the healthcare provider (Weslien et al., 2005). Often, upon reflection, the significant other feels guilty because of feelings of inadequacy during the event or of worry about not performing CPR correctly (Bremer et al., 2009; Holm et al., 2012; Weslien et al., 2005). To relieve this guilt, the significant other often seeks forgiveness from health care providers by seeking their assurances that he or she did everything possible to help his or her loved one (Bremer et al., 2009). If resuscitation efforts were prolonged, family members describe a feeling of anxiety about their loved one suffering permanent cerebral damage (Weslien et al., 2005). If there was sustained uncertainty about the patient's outcome after cardiac arrest, the significant other's suffering was increased (Bremer et al., 2009).

In the subacute phase after the cardiac arrest, partners expressed a need for relevant information, care, and attention (Bremer et al., 2009). Families who were required to wait at the hospital before seeing their loved one, experienced uncertainty and disappointment because they received no information about their loved one (Larsson et al., 2013). Additionally, if the patient survived the cardiac arrest, the significant other often experienced worry about a recurrence of cardiac arrest and risk of death (Bremer et al., 2009; Wallin et al., 2013). This concern was more pronounced if the cause of the cardiac arrest remained unknown (Wallin et al., 2013). Studies have shown that these families experienced more symptoms of anxiety than patients after discharge from ICU (Young et al., 2005). Despite this, the significant others often kept their fears to themselves, so as to not worry their loved one (Bremer et al., 2009).

Though families described a need to talk about what had happened (Wallin et al., 2013), this lack of ability to talk about their fears lead to the significant other experiencing loneliness

(Bremer et al., 2009). Young et al. (2005) also pointed out that the ICU patient often has no memory of his or her ICU admission; this lack of shared memory between the family member and patient added a psychological burden to the family member that in turn contributed to his or her experience of anxiety. A loved one's cardiac arrest has a profound impact on the significant other's emotional well-being (Uren & Galdas, 2014), and often he or she struggles with sleep disturbances, difficulties relaxing, and permanent emotional distress (Wallin et al., 2013). Wallin et al. found that families of patients who survived cardiac arrest expressed a need to share their experiences with others. However, Dougherty and Thompson (2009) found that family social support was very low in the first year after cardiac arrest. Weslien et al. (2005) noted in their study that healthcare providers played an essential role in guiding family members so that they could regain their state of equilibrium after witnessing their loved one's cardiac arrest.

Four qualitative studies (Ann-Britt et al., 2010; Bremer et al., 2009; Holm et al., 2012; Weslien et al., 2005) and one quantitative study (Dougherty & Thompson, 2009) were found to primarily investigate the significant other's experience of cardiac arrest. Only three qualitative studies were found that explored the experience of other family members such as children, siblings, and parents (Larsson et al., 2013; Löf et al., 2010; Wallin et al., 2013). These studies identified that during a loved one's cardiac arrest, family members often feel shock, fright, helpless, a sense of unreality, and also feelings of guilt that they did not do enough (Ann-Britt et al., 2010; Bremer et al., 2009; Holm et al., 2012; Larsson et al., 2013; Löf et al., 2010; Weslien et al., 2005). Though some family members could not bear to watch the resuscitation efforts (Löf et al., 2010), others disliked being separated from their loved one (Weslien et al., 2005).

Some family members found the most difficult time of a cardiac arrest event was during or after their loved one's discharge home, when they suffered sleep disturbances, difficulties

relaxing, and fear of recurrence (Dougherty & Thompson, 2009; Wallin et al., 2013). Although these studies offer valuable insight into family members' experiences during a loved one's cardiac arrest, there is some ambiguity about whether the experiences differed based upon the family members' relationship to the patient, and if they were present for the cardiac arrest event. These studies also did not explore the family members' lived experience of a loved one's TTM; TTM is immediately intertwined with cardiac arrest according to current treatment recommendations (Callaway et al., 2015). Additionally, research methods were primarily qualitative content analysis, and only two studies utilized a phenomenological approach to explore the lived experience of family members during this event (Bremer et al., 2009; Holm et al., 2012). These studies have also indicated that more research about this phenomenon is needed; doing so will better enable healthcare professionals to support and care for these individuals (Ann-Britt et al., 2010; Bremer et al., 2009; Holm et al., 2012).

Clearly, as identified above, the negative effects of a loved one's cardiac arrest are significant (Ann-Britt et al., 2010; Wallin et al., 2013). The literature reveals that the experiences of family members in this situation are both complex and varied. Not only are family members impacted by a loved one's cardiac arrest, they are also impacted by situations and events that occur both immediately after the event and also after discharge home. To further explore what is currently known about the families' experience of a loved one's general critical illness, a review of the literature is provided below.

### **Families' Experience of the Intensive Care Unit and Critical Illness**

The experience of touching a loved one's cold skin or anticipation of the awakening after completion of TTM would not be a part of the lived experience for all families of critically ill patients after cardiac arrest. However, families of general critically ill patients are in an

uncertain situation where they may be feeling fragile, vulnerable, and stressed (Al-Mutair, Plummer, O'Brien, & Clerehan, 2013; Christensen & Probst, 2015; McConnell & Moroney, 2015). Despite being prepared by nurses as to what to expect, family members experience shock when they see their loved one for the first time in ICU (DiSabatino Smith & Custard, 2014; McKiernan & McCarthy, 2010). Christensen and Probst point to the technological environment of the ICU, as well as the intrinsic uncertainty and confusion of an ICU admission, as factors that add to the families' experience of stress. Indeed, critical illness and admission to ICU of a loved one can have a significant impact on the families' psycho-social well-being (van Mol et al., 2014).

The ICU environment itself poses its unique challenges for family members of critically ill patients. In one study, families felt helpless when they saw their loved ones tied down with tubes (Wallin et al., 2013). In another, the ICU environment was found to be frightening, and though families were able to visit the patient, they felt they were in the way of the ICU staff (Larsson et al., 2013). This finding is in contrast to findings by Löf et al. (2010), who found that families felt welcomed to go into the ICU at any time and were given the opportunity to sleep next to their loved one. This welcoming ICU environment led families of patients who were receiving TTM to feel safe and secure (Löf et al., 2010). Although some families described the ICU equipment as frightening (Holm et al., 2012), others perceived the equipment as proof of professional monitoring. This inspired feelings of safety so that families felt comfortable to leave their loved ones for periods of time (Holm et al., 2012; Löf et al., 2010). Families found that the thoughts of a potential injury that their loved one may have sustained were worse than being in the ICU environment (Larsson et al., 2013). In a literature review conducted by Paul and Rattray (2008), hope was identified as an important need for families of critically ill patients. Similarly

in the context of a patient's treatment with TTM, partners experienced mixed feelings of hope and hopelessness (Holm et al., 2012). Nonetheless, the need to feel hope was described as important and gave family members strength (Larsson et al., 2013; Löf et al., 2010)

In a study by Agård and Harder (2007), it was found that families of critically ill patients are on a journey where they are constantly trying to adapt to their new situation. Family members want to feel included and help their critically ill loved one, but do not know how to do so (Agård & Harder, 2007; Frivold et al., 2015). Many studies identify that family members wish to remain close to their critically ill loved one (Agård & Harder, 2007; Al-Mutair et al., 2014; Khalaila, 2013; McKiernan & McCarthy, 2010). The opportunity to participate in the care and decision-making around their loved one makes families feel safe and grateful; conversely, a lack of involvement increases a perceived lack of understanding which can be painful and frustrating (Frivold et al., 2015). The impact of an ICU admission on families can be so severe that it results in the family member experiencing Post Traumatic Stress Disorder (PTSD) (Christensen & Probst, 2015). Dithole, Thupayagale-Tshweneagae, and Mgutshini (2013) found that spouses of critically ill patients were disproportionately at increased risk of developing PTSD. Even more alarming, Azoulay et al. (2005) found that one-third of families of critically ill patients experienced symptoms of PTSD at 90 days after the patient's death or discharge from ICU.

Family members experience intense feelings and severe anxiety when they do not know the prognosis of their loved one (Al-Mutair et al., 2014). Agård and Harder (2007) found that families used the strategy of enduring as a coping strategy. This involved the families suppressing their anxiety and sorrow as a way to cope with the intense pressure of their loved one's current situation. Agård and Harder also found that families endured alone and in silence, and often did not share this with the nurses.

The family members' need for honest and accurate information about their loved one's condition is repeated throughout the literature (Agård & Harder, 2007; Al-Mutair et al., 2014; Frivold et al., 2015; Khalaila, 2013; McKiernan & McCarthy, 2010). Moreover, Azoulay et al. (2005) found that the perceived incompleteness of information was associated with the development of post-traumatic stress reaction in family members of critically ill patients. Similarly, Frivold et al. asserted that a lack of information might be perceived as a lack of honesty thereby causing the families of critically ill patients to feel confused, worried, and frustrated; this may then lead to a loss of confidence in the health care team. Family members experience uncertainty and worried when a loved one is admitted to ICU; these feelings are connected to their loved one's prognosis and condition (Frivold et al., 2015). Al-Mutair et al. and Frivold et al. found in their studies that provision of quality information to family members supported the family in anticipating and accepting what may happen in the future, and this resulted in improved coping and reduced stress. Additionally, information that is provided at the time of the patient's admission to ICU needs to be repeated because family members are unable to absorb the initial information (McKiernan & McCarthy, 2010). Agård and Harder found that the provision of information does not always relieve families' anxiety when they are searching for answers as to whether their loved one would survive or if he or she would have disabilities. Sometimes, there are no answers for the questions asked by families of critically ill patients. Families may actively seek information, but the reassurance they may feel is fleeting (Agård & Harder, 2007).

In addition to informational support, other family members such as spouses, siblings, parents or children, are identified as an important source of support to families in ICU (Frivold et al., 2015; McKiernan & McCarthy, 2010). Staying together as a family provides comfort and

strength for families of critically ill patients (Frivold et al., 2015). Family members also describe their need for hope during their loved one's ICU admission; the experience of hope is reassuring to families, and it assists with their coping (McKiernan & McCarthy, 2010).

### **Nursing Care of the Family of the Critically Ill Patient**

Intensive care nurses not only care for the critically ill patient, they also care for their patients' family members as well (Agård & Harder, 2007; Al-Mutair et al., 2013; McConnell & Moroney, 2015; McKiernan & McCarthy, 2010). Surprisingly, however, in a mixed methods study by McConnell and Moroney, critical care nurses held the belief that a patient's admission to an ICU would not significantly impact the lives of the family members. Contrary to this belief, the families' experience in ICU may directly affect their health and well-being (DiSabatino Smith & Custard, 2014). Khalaila (2013) asserts that critical care nurses should place the family and critically ill patient together as the focus of nursing care to improve the quality of care delivered in ICU. Agård and Harder found that family members of critically ill patients appreciated when the nurse invited them to stay at the bedside and participate in the care of their loved one: reading aloud to the patient, wiping their face, or providing mouth care.

Intensive care nurses also play a crucial role in supporting families as they try to absorb and understand information given to them while in the ICU environment (Frivold et al., 2015; McKiernan & McCarthy, 2010). DiSabatino Smith and Custard (2014) found that to reduce anxiety, family members sought to have ICU staff tell them the same information more than once. Nurses provide direct support to families in these situations, and also act as a facilitator for other forms of support, such as arranging a location for family members to be together during times of stress (Frivold et al., 2015; McKiernan & McCarthy, 2010). Families have found that nurses provide most of the information they need, and this provides them with reassurance and

specifically nurses who gave information freely, without being asked were particularly appreciated (McKiernan & McCarthy, 2010). Additionally, the constant presence of the nurse at the bedside promotes feelings of security for the family (McKiernan & McCarthy, 2010). Other nursing characteristics that are comforting to family members of critically ill patients included the perception that the nurse really cared for their loved one, and that the nurse is knowledgeable and competent (McKiernan & McCarthy, 2010). Intensive Care Unit nurses are well positioned to care for both the critically ill patient and his or her family (Agård & Harder, 2007; McConnell & Moroney, 2015). To care for these individuals, knowledge of their unique experience is essential so that the nurse can meet their needs (Löf et al., 2010).

### **The Family Member's Experience of Targeted Temperature Management**

As noted above, the literature identifies that the experience of a loved one's cardiac arrest is traumatic and has a significant impact on the family members' mental health (Ann-Britt et al., 2010; Wallin et al., 2013). Furthermore, an ICU admission for TTM following cardiac arrest is unique from other ICU admissions for families; it is a sudden, unexpected event that brings their lives to a halt (Löf et al., 2010). Moreover, there is significant uncertainty about the patient's future because prognostication is not reliable until at least 72 hours after the event (Callaway et al., 2015). The experiences of family members in this unique situation have received little attention in the literature (Löf et al., 2010).

Family members of patients admitted to ICU for TTM have stated that they were unprepared to see their loved one so changed from before the event; seeing them connected to tubes and other equipment was traumatic and some families described the patient as looking much older than before (Löf et al., 2010). Although families were informed that the patient would be cooled down to 33°C, they found touching the patient to be difficult because his or her



skin looked and felt different than normal; the patient looked and felt 'like death' (Löf et al., 2010). The study by Löf et al. provides some valuable information about the relatives' experience of a loved one's cardiac arrest and subsequent treatment with TTM: an intense, incomprehensible, and unreal experience. However, this study did not utilize a phenomenological method to reveal the lived experience of the participants; rather, qualitative content analysis was utilized for this study. Additionally, the study was conducted in one hospital in Northern Sweden and the authors acknowledge this as a limitation and recommend further studies be conducted in different locations and cultures (Löf et al., 2010).

Also through the use of content analysis, Larsson et al. (2013) conducted a qualitative study to describe the family's experience of a loved one's treatment with TTM and found that families described the feeling of pain they experienced when they saw their loved one, who felt cold and dead to touch, in ICU. Families stated that it was especially difficult for younger children to see one of their parents so seriously ill (Larsson et al., 2013). As with the study by Löf et al. (2010), Larsson et al. conducted their study in Sweden with participants who could read and understand Swedish; as such this may present a limitation because the study findings may be unique to the geographical location and culture of Sweden.

Similarly, Wallin et al. (2013) utilized a qualitative content analysis approach, to reveal that families perceived it to be unpleasant to see their loved one pale and cold to touch when they reached the target temperature for TTM. This study did reveal some valuable information regarding the family members' experiences of the event. However, the stated aim of Wallin et al.'s study was to describe the family members' experiences 6 months after their loved one's survival from cardiac arrest and treatment with TTM. Therefore, this study is limited in its ability to fill the current gap in knowledge regarding the lived experience of families of patients

who receive TTM after cardiac arrest. Additionally, as with the previous studies, this study was set in Sweden, and therefore may be limited in its applications to other geographical locations and cultures.

In contrast to Wallin et al.'s (2013) findings, Holm et al. (2012) conducted a phenomenological study that focused on the partner's experience of a loved one's cardiac arrest and subsequent treatment with TTM. The researchers found that families did not describe their loved one's cold body to be traumatic; rather they viewed the cold body as merely an essential part of the treatment. This research was conducted using Giorgi's phenomenological psychological method with the aim to describe the experiences of partners of patients who survived cardiac arrest and treatment with TTM. This study attempted to fill the identified gap in knowledge using a phenomenological method, however, the researchers focused solely on the partners' experience and excluded other family members from participating. As with the other Scandinavian studies that have explored the family members' experiences of this phenomenon, this study was conducted in Norway. This again may limit the ability to understand the phenomenon of interest in other geographical locations or cultures.

During the time of TTM, families have described difficulty in understanding and absorbing the situation they were in (Larsson et al., 2013). They put themselves second, took time off work, and were consumed with thoughts of their loved one (Löf et al., 2010). Families found it difficult to be near their loved one, yet unable to influence the situation (Löf et al., 2010). In the study by Löf et al. families described relationships with other people as valuable and they drew important support from friends and other family members. They felt that when they visited the patient, they were less lonely when they had someone with them to talk to (Löf et al., 2010). This finding was also identified by Larsson et al. where family support was perceived as the most

important, but also support from close friends, colleagues, and employers was felt to be beneficial. This finding is in contrast to Holm et al.'s (2012), findings where partners describe ambivalent feelings about visitors; they understood the visitors' good intentions, however they felt the visitors consumed their resources and took time away from the patient and the partner's immediate family.

Holm et al. (2012) and Löf et al. (2010) found that partners experience the time spent awaiting the awakening of their loved one to be the most difficult time of the entire treatment. This was a time of constant suspense where every movement or sign that may indicate a change in the patient's situation caused strong emotions for partners of patients. Worry about whether or not their loved one sustained injuries was a powerful cause of stress for families (Larsson et al., 2013). Survivors of cardiac arrest who do not suffer significant brain injury usually recover responsiveness within 24 to 48 hours after the cardiac arrest; however, with the sedative and paralytic agents used to induce TTM, indications of neurological recovery is obscured within this time frame (Taccone et al., 2014). When sedation is weaned during rewarming after TTM is complete, patients may show neurological improvement over the following days or they may remain unresponsive which is associated with a worsening prognosis (Taccone et al., 2014).

Larsson et al. (2013) found that families felt uncertainty, anxiety, and fear about the future because they were worried about physical and mental changes in their loved one. It was during this time of anticipation of the awakening that partners felt compelled to be close to their loved one, especially if the patient was in a deep coma (Holm et al., 2012). If the patient woke up and recognized his or her partner, the partner and other family members felt great relief (Holm et al., 2012; Löf et al., 2010). Alternatively, if the patient awoke and did not recognize his or her partner, the partner was extremely concerned that this condition would be permanent

(Holm et al. 2012). Despite this, Lof et al. found that families remained hopeful.

Holm et al. (2012) noted that partners stated that information given to them that was based on realistic facts helped them to maintain hope. In contrast, families also described how a lack of information, or information that changed from time to time caused them to experience increased anxiety (Löf et al., 2010). Moreover, partners also experienced anxiety upon their loved one's discharge home (Holm et al. 2012). Wallin et al. (2013) found that families of patients who received treatment with TTM after cardiac arrest had ongoing negative effects six months after the experience: difficulties relaxing, sleep disturbances, fears of recurrence, and a permanent state of emotional distress.

Clearly, it is of interest and importance to nursing to care for families of patients who are receiving TTM after resuscitation from cardiac arrest. The family members' experience of a loved one's successful treatment with TTM is unique from other critical illness experiences; the sudden, unexpected event, the delay in prognosis, and feeling the patient's cold skin are contributing factors to this experience. However, a better understanding of the family members' experience of TTM after cardiac arrest is required before an intervention can be devised and tested. To date, only four studies have explored this phenomenon (Holm et al., 2012; Larsson et al., 2013; Löf et al., 2010; Wallin et al., 2013), and all were completed in Scandinavia. Three of these studies used qualitative content analysis to explore families' experiences of TTM after cardiac arrest, and one of these focused on the experiences 6 months after the event. The fourth study used a phenomenological approach to examine only the partner's experiences of cardiac arrest and TTM. As stated by Holm et al., more studies are needed in this area. Knowledge of the families' experience during this difficult time is a prerequisite for nurses to be able to meet their unique needs (Löf et al. 2010). To date, no study utilizing the phenomenological approach

to reveal the families' lived experience of TTM after a loved one's cardiac arrest has been conducted in North America. This study aims to fill this gap.

### **Nursing Perspective**

The metaparadigm of nursing consists of four concepts: human beings, environment, nursing, and health (Fawcette & DeSanto-Madeya, 2013). Because humans are a central concept to the discipline of nursing, it is crucial that nurses utilize a research tradition that enables researchers to both understand and describe the human experience (Streubert & Carpenter, 2011). Though the generation of nursing knowledge is dominated by the positivist scientific method (Pratt, 2012), scholars question the value of information about human phenomena that is generated from a purely objective standpoint (Streubert & Carpenter, 2011). A constructivist tradition emphasizes the concept that humans create their own experiences and that multiple realities exist (Polit & Beck, 2012; Streubert & Carpenter, 2011). As a discipline, nursing values the uniqueness of individuals (Earle, 2010). It is of interest to nursing to gain an understanding of the lived experience of people (Pratt, 2012; Salmon, 2012); doing so enables nurses to care better for and promote the well-being of their patients and families as they experience unique and unfamiliar experiences (Matua, 2015). Phenomenology, as a research method, enables nurses to understand their patients' insights into their own unique experiences (Cody & Mitchell, 2002). By using a phenomenological method to better understand the family's lived experience of a loved one's successful treatment with TTM after cardiac arrest, nurses may better care for these families.

### **Researcher's Presuppositions**

According to Giorgi's phenomenological psychological method (2009), the researcher must bracket his or her past knowledge and experience about the phenomenon of interest so that

a fresh approach is utilized to analyze the data. Therefore, through bracketing, the resulting description of the phenomenon of interest is understood to be what the research participant experienced (Giorgi, 2000). The following presuppositions have influenced me and are foundational for my research:

1. Striving to understand a patient's unique experience and how he or she interprets this experience is a key component of ethical nursing care.
2. Enhanced knowing of patients' lived experiences enables the nurse to better care for both patients and their families (Matua, 2015).
3. Witnessing a significant other's cardiac arrest is a traumatic experience for family members who often feel guilty after the event (Ann-Britt et al., 2010; Bremer et al., 2009)
4. Treatment with TTM after cardiac arrest delays prognostication for more than 3 days; this increases the families' feelings of uncertainty and anxiety (Larsson et al., 2013).
5. Seeing their loved one in ICU after cardiac arrest during treatment with TTM is a frightening and painful experience for families (Larsson et al., 2013).
6. Treatment with TTM results in the patient feeling cold and almost dead to families (Larsson et al., 2013).
7. Awaiting the awakening after TTM is the most difficult time for family members; a time filled with constant suspense (Holm et al., 2012).
8. The experience of a loved one's treatment with TTM after cardiac arrest is different for different members of the family.
9. Critical care nurses care for both the patient and his or her family and play a key role in supporting the family members both during and after the acute phase of TTM.
10. Because the survivor of cardiac arrest has no memory of the event or treatment with TTM,

a lack of shared memory exists between the patient and family, and this contributes to a psychological burden for family members (Young et al., 2005).

11. The lived experience of family members during a loved one's treatment with TTM is not well understood.

12. Utilizing the phenomenological approach will provide the information to answer the research question of this proposed study.

Through the identification of presuppositions, I aim to shift attitude so that I am fully present to the descriptions of the phenomenon given by the participant, rather than be present to this phenomenon in a habitual fashion as I have been in the past (Giorgi, 2009).

### **Summary**

Although four studies have been conducted to explore the family members' experiences of a loved one's cardiac arrest and TTM, a significant gap in knowledge remains regarding the lived experience of this phenomenon. Of the four studies that have been conducted, three utilized a content analysis approach to describe the experience (Larsson et al., 2013; Löf et al., 2010; Wallin et al., 2013), and one of these focused on the family members' experiences 6 months after the event (Wallin et al., 2013). One study utilized a phenomenological approach to describe the lived experience of this phenomenon; however, only partners of patients were interviewed, and other family members were excluded from the study. All four studies were conducted in Scandinavia, thereby limiting their ability to inform nursing practice that is set in different geographical locations or cultures.

A gap in knowledge exists around the family members' lived experience of a loved one's cardiac arrest and subsequent successful treatment with TTM outside of Scandinavia. This study aimed to fill this gap in knowledge by utilizing Giorgi's (2009) phenomenological psychological

method to collect data from participants living in Eastern Canada who were family members of the patient who experienced the cardiac arrest and were treated with TTM.



## **CHAPTER 3**

### **Method**

A descriptive, phenomenological method was used to explore the family's experience of a loved one's successful treatment with TTM. The phenomenological approach is most appropriate in situations where the phenomenon of interest has been poorly conceptualized (Polit & Beck, 2012). As such, this method of inquiry was appropriate for the aim of this study as the concept of the lived experience of families of patients undergoing TTM after cardiac arrest has been poorly defined. In the following section, I will describe the research method that was utilized for the study including a brief description of Giorgi's phenomenological approach, study participants, data collection strategies, study setting, data analysis, ethical considerations, strategies to enhance trustworthiness, and plans for dissemination of the results.

#### **Giorgi's Phenomenological Psychological Approach**

The phenomenological psychological method described by Giorgi (2009) was used to guide this inquiry. Giorgi's method is based on Husserl's philosophy, which describes meanings as originating from relationships between the consciousness and objects (Giorgi, 2009). The philosophical phenomenological method, as proposed by Husserl involves the philosopher moving from a natural attitude to a phenomenological attitude, searching for the essence of a phenomenon through free imaginative variation using the process of intuiting acts (signifying, fulfilling, and identifying), and then describing the phenomenon as accurately as possible (Giorgi, 2009). Giorgi modified Husserl's philosophical phenomenological method to meet scientific criteria of analysis; his phenomenological psychological method is a synthesis of philosophical phenomenology, a human science perspective, and psychology (Giorgi, 2009).

Giorgi's (2009) method involves first obtaining descriptions from others who have lived

through the experience of the phenomenon of interest. These descriptions are the raw data, and are descriptions that are “as faithful as possible to the actual lived-through event” (Giorgi, 2009, p. 96). Prior to analyzing these data, the researcher must assume the phenomenological attitude whereby the raw data are understood to be how the participant experienced the phenomenon; no judgment is made as to whether or not the descriptions actually occurred as they were described (Giorgi, 2009). In addition, the researcher’s past experiences and knowledge are bracketed so that this prior knowledge does not interfere with the present analysis of the phenomenon as experienced by another (Giorgi, 2009). Although bracketing is thought by some to be impossible to achieve fully (Streubert & Carpenter, 2011), Giorgi argues that one is not required to forget his/her past knowledge of the phenomenon; rather, a heightened awareness of the present experience is all that is required.

Additionally, Giorgi (2009) acknowledges that while complete bracketing may not be achievable within a philosophical context, it is achievable within a psychological context. Therefore, when using Giorgi’s method, it is essential that I, as a researcher, reflect and bracket my pre-understanding of the phenomenon of interest gained by my previous 19 years of experience in ICU; in doing so, I remain open and sensitive to the phenomenon of interest (Corrigan, Samuelson, Fridlund, & Thome, 2007). I utilized bracketing in a continuous fashion throughout the research process through the use of a reflexive journal. In this journal, I noted personal values and assumptions, identified feelings that may have led to a loss of neutrality, and also described surprising or interesting findings that were revealed during data collection and analysis.

## **Participants**

Participants were recruited through a purposive and snowball sampling strategy of

families of patients admitted to ICU for successful treatment with TTM after cardiac arrest. Frivold et al. (2015), consider spouse, child, sibling, and grandchild to be close family members for inclusion into their family orientated qualitative research in ICU. For the purpose of this research, family was defined as partner, sibling, child, or parent. All individuals who were considered to be a family member, as defined, of a patient who had undergone successful treatment with TTM after cardiac arrest and survived to hospital discharge, were considered for inclusion. To be eligible, participants must have been a family member of a patient who received successful TTM in the Maritimes, been 18 years of age or older, spoke and understood English, were willing to share their experience, and at least 2 months had passed since their loved one's event, but not more than 24 months.

Once ethical approval for this study was obtained from the University of Prince Edward Island (UPEI) Research Ethics Board, approval was sought and obtained from the Health Prince Edward Island (PEI) Research Ethics Board. Upon approval from the two research ethics boards, I then commenced the study. To recruit participants, I received support from the Queen Elizabeth Hospital (QEH) ICU Nurse Manager, the QEH Director of Nursing, and the Chief Administrative Officer of the QEH (see Appendix A). Although I am employed as the Clinical Nurse Educator in the QEH ICU, I had no contact with the potential participants prior to their decision to participate in the study. I provided the ICU Nurse Manager with the inclusion criteria for the study. The Nurse Manager then accessed the ICU admission book, to which she has access on a daily basis to fulfill her duties of employment, and retrieved the names of patients who met the inclusion criteria of the study. She then accessed their chart to retrieve the contact details of their next of kin. Once she obtained the contact details of these potential participants, she telephoned them to inform them of the study utilizing a script prepared by

myself (see Appendix B). At the end of the script, the potential participants were offered the opportunity to access a Facebook page that contained the letter of invitation for more information about the study, and also my office telephone number to call if they or anyone else in their family were interested in participating in the study.

The letter of invitation was directed to the patient's next of kin, and offered the opportunity for the participants to refer other members of their family (as defined previously) to participate in the study. This letter described the purpose and procedure of the study, as well as the voluntary nature of the study and the potential participants' right to withdraw from the study at any time. The letter also included my office telephone number and email address for the potential participants to contact if they would like to participate in the study, or if they had any questions. For the potential participants who decided to call, I determined if they met the inclusion criteria of the study at the time they initially contacted me. Those who met the inclusion criteria were invited to participate in the study. If they agreed to participate, they were asked to sign a written consent form (see Appendix D) when they met with me, prior to the interview commencing. Other studies have utilized similar recruitment strategies. In a study examining the spouses' experiences of witnessing a loved one's cardiac arrest at home (Ann-Britt et al., 2010), medical records of survivors and non-survivors of cardiac arrest were reviewed for their spouse's contact details. A letter of invitation was then sent to the spouse, and the researchers followed up the invitation with a phone call invitation 1 week later (Ann-Britt et al., 2010). Similar styles of recruitment were utilized by Frivold et al. (2015) and Weslien et al. (2005).

Potential participants were contacted no earlier than 2 months after their loved one's cardiac arrest and successful treatment with TTM. Although some authors expressed concern

that interviewing participants within 6 months of a cardiac arrest event may interfere with the acute grieving process (Bremer et al., 2009), many other studies investigating families' experiences with cardiac arrest and other critical illness interviewed participants within 1 to 2 months (Engström & Söderberg, 2004; Frivold et al., 2015; Weslien et al., 2005). Moreover, Bentley and O'Connor (2015) conducted a study to determine the most appropriate time to interview bereaved family carers. They found that most family members were willing to be interviewed within 5 months of their loved one's death, and many were willing to be interviewed within weeks of the event (Bentley & O'Connor, 2015). In this study, participants reported no distress from being interviewed; in fact they identified that they preferred being interviewed soon after their loved one's death because they wanted to talk about their experiences (Bentley & O'Connor, 2015). In the present study, interviews occurred between 2 and 24 months following the patients' cardiac arrest and successful treatment with TTM. According to Addington-Hall and McPherson (2001), the shorter the time between the event and the recollection, the easier it is for participants to recall the event. However, Ann-Britt et al. (2010) found that spouses' descriptions of their loved one's cardiac arrest up to 27 months after the event were so detailed, it seemed as though the event happened very recently. This timing is similar to other studies (Bremer et al. 2009; Weslien et al. 2005).

According to Giorgi (2009), at least three participants are required for phenomenological research so that important variations in the raw data are captured. Therefore, nine family members who experienced the phenomenon of interest and met the inclusion criteria were recruited, to ensure data saturation was reached. Data saturation occurs when data are found to be repeating and no new themes are emerging (Streubert & Carpenter, 2011) and or the participant states that this is his or her experience and that there is nothing more to share.

Obtaining diversity and variations in raw data around the phenomenon of interest is important; therefore, family members including partner, sibling, child, and parent were recruited to the study (Giorgi, 2009; Streubert & Carpenter, 2011).

### **Pilot Study**

A pilot study was conducted with three family members of patients who had received TTM after cardiac arrest before commencing the larger study. Beginning with a pilot study enabled me to determine the adequacy of the study design. Also, through the use of a pilot study, I was able to access support from my thesis supervisor when initially using Giorgi's method, thereby ensuring that I was applying the method accurately. The data from the pilot study was included in the larger study.

### **Data Collection**

Phenomenological inquiry involves the researcher helping the participants to describe the lived experience of the phenomenon of interest; the researcher should not lead the discussion, rather he or she should ask probing, open-ended and clarifying questions during the interview (Streubert & Carpenter, 2011). During the interview, it is crucial that the researcher remains focused on the data and listens attentively, while treating the participants with respect and interest in their experience until the participants believe that they have exhausted their description of the phenomenon of interest (Streubert & Carpenter, 2011).

Data were collected through digital-audio taped, one-on-one interviews, using a semi-structured interview style (see Appendix E). I opened the interview with a grand tour question: Can you describe your experience when *name* had the cardiac arrest and then was treated with the cooling treatment? Subsequent questions asked by me were guided by the participant's responses and aimed to reveal rich descriptions of the phenomenon of interest (Polit & Beck,

2012). Areas of exploration included the feelings and emotions experienced by participants when they first learned of the cardiac arrest during the patient's treatment with TTM and the time during which they awaited the patient's awakening. Additionally, to obtain the most accurate and comprehensive description of the lived experience of the phenomenon as possible, I maintained a journal of notes generated during the interviews. Journaling during data collection also facilitates phenomenological reduction whereby the researcher's beliefs and assumptions are held separate from the raw data and assists the obtainment of the purest possible description of the phenomenon of interest (Streubert & Carpenter, 2011).

### **Setting**

One-on-one interviews took place in a private room in the School of Nursing at UPEI, or if the participant preferred, in a private room at the local hospital. Participants were contacted to arrange for an interview at least 2 months after the patient's cardiac arrest and successful treatment with TTM.

### **Data Analysis**

Giorgi's (2009) phenomenological psychological method was utilized to analyze the transcribed data. The aim of this method was to determine meanings of the phenomenon of interest (Whiting, 2001). To enhance the reliability of the analysis so that the true constituents of the phenomenon of interest were revealed, I utilized: bracketing; the intuitive acts of signifying, fulfilling, and identifying; and free imaginative variation as describe by Giorgi. The steps in Giorgi's method are as follows: (a) read the transcribed data to get a sense of the description of the phenomenon; (b) reread the transcriptions so that the description is broken down into meaning units; (c) go back to the meaning units to discover a way to express the implications of these meaning units in the language of science; (d) while maintaining attentiveness to the present

descriptions of the phenomenon with bracketing, use imaginative variation to distinguish and clarify meaning units; and (e) synthesize the meaning units into a precise description of the family's experience of a loved one's successful treatment with TTM after cardiac arrest as it presents itself to the researcher (Giorgi; Streubert & Carpenter, 2011). In addition to the qualitative analysis, descriptive statistics were utilized to analyze the demographic data of the participants.

### **Ethical Considerations**

Ethical approval was first obtained from the UPEI Research Ethics Board (see Appendix F), and then from the Health PEI Research Ethics Board (see Appendix G), prior to the commencement of this study. Patients who received TTM in ICU were identified by the ICU Nurse Manager from the ICU admission book as described previously. Participant confidentiality was maintained by conducting the interviews in a private office at UPEI, or if the participant preferred, a private room at the local hospital, and through the coding of the interview data. These steps were taken to safeguard the participants' personal information, privacy, and enhance their anonymity when participating in the study. I maintained a confidential notebook of the study; this notebook contained a key linking names to codes on the data, to which only myself and my committee had access. This notebook was locked in a drawer in a separate location from the digital audio-recordings and research notes.

Only myself, my supervisor, and the transcriptionist, who was required to sign a contract of confidentiality, had access to the digital audio-recordings and transcriptions. The digital audio-recordings were stored on a Universal Serial Bus (USB) key and transferred to my laptop which was protected by a password. A separate journal was also used to record my thoughts, feelings, and reactions during data collection and analysis to enhance trustworthiness. The research



notebook, digital audio-recordings, transcriptions, and journal will be secured and held for 5 years, after which time I will destroy these data. Participants' anonymity will be maintained when the research findings are published; pseudonyms will be used to conceal each participant's identity and other identifying descriptors such as the location of events and names of family members will be concealed.

The letter of information which was provided to participants detailed the purpose of the research, as well as the risks and benefits to the participants. The risks to participants included: the burden of time for the interview (approximately 1 to 2 hours) and a risk of psychological harm related to feelings raised during the interview. To reduce the risk of psychological harm, I ensured that counselling services were available for families after the interview. Support was available from myself as I have expertise as an ICU Registered Nurse (RN) in the care of families of critically ill patients who have received TTM. Additionally, I had access to my thesis supervisor who is a trained counsellor, and who agreed to be available to support research participants after interviews if necessary. If further counselling services were required, the participant would have been provided with the telephone number of the local Community Mental Health Centre. The benefit to participants was that they had an opportunity to reflect upon and share their experience about their loved one's treatment with TTM. Indeed, Wallin et al. (2013) found that families expressed a need to share their experiences with TTM after cardiac arrest with others.

When a potential participant initially contacted me by phone, he or she was screened as to whether or not he or she was eligible to participate. Those who met the inclusion criteria were invited to participate in the study. At the first meeting between myself and the participant, the participant was offered the letter of invitation (Flesch-Kincaid Grade Level 8.2), and if he or she

wished to proceed with study participation, he or she was asked to sign a letter of consent (Flesch-Kincaid Grade Level 6.9). Prior to the potential participant signing the consent form, I offered to read the letter of invitation and consent form to him or her. I ensured that families were informed that participation was voluntary and that they could withdraw from the study at any time. Once families provided their written consent to participate in the study, I reviewed with them how the interview would occur and then answered any questions they had. At this time, participants were also asked for permission to digitally audio-record the interview. In addition to written consent, I also utilized the concept of process consent with participants. Process consent refers to collaboration between the researcher and participant, whereby the participant's consent to continue in the research is renegotiated in an ongoing manner (Polit & Beck, 2012).

In an effort to communicate to participants my respect and concern for their well-being, I provided participants with the opportunity to debrief (Polit & Beck, 2012). Debriefing occurred at the conclusion of the interview, when the participants were given the opportunity to ask questions or provide feedback. I have a significant amount of experience as a critical care nurse, and more than 10 years of experience with the administration of TTM after cardiac arrest. Additionally, participants were offered the option to receive, by mail, a copy of the research findings.

### **Trustworthiness**

To enhance the trustworthiness of the research findings, I utilized Guba and Lincoln's (1989) criteria of trustworthiness: credibility, transferability, dependability, confirmability, and authenticity. Research findings are credible when the researcher's description of the participant's experience of a phenomenon matches the participant's actual lived experience of the

phenomenon (Guba & Lincoln, 1989). To increase the credibility of the research findings, I: utilized prolonged engagement with the study participants during interviews; engaged in persistent observations during these interviews by maintaining a journal of thoughts, feeling, and observations noted during interviews; engaged in peer debriefing to assist me in understanding my own values in relation to the data collection and analysis; and employed progressive subjectivity through ongoing bracketing and the use of intuiting (Giorgi, 2009; Guba & Lincoln, 1989).

Transferability refers to the degree to which the researcher provides the audience with enough descriptors of the context within which the phenomenon occurred, so that the audience can then determine how transferable the study findings are to other situations (Guba & Lincoln, 1989). To increase transferability, I provided a thick description of the research findings in the study report.

According to Guba and Lincoln (1989), dependability in a qualitative study refers to how much a researcher has made available to the audience the decisions that were made regarding methodological changes during the inquiry. In this style of research, methodological changes that occur with an emergent design result in a successful inquiry (Guba & Lincoln, 1989).

Confirmability in a study indicates that the outcomes of the study are rooted in the context of the participant's experience, and not simply the researcher's interpretation of the experience (Guba & Lincoln, 1989). Dependability and confirmability were increased through maintaining a log of decisions made during the study, through describing these methodological decisions in the research report, and by making explicit how I moved from the raw data to the final description of the phenomenon of interest.

Authenticity in a study is achieved when the researcher effectively communicates to the

audience the range of realities experienced by participants; a report is authentic if the reader can vicariously experience the phenomenon of interest (Polit & Beck, 2012). Authenticity was enhanced through the researcher's faithful communication of the participants' realities to the readers of the master's thesis. Additionally, to ensure that the true constituents of the phenomenon were identified during data analysis, Giorgi's (2012) criteria of phenomenological reduction and intuiting were utilized.

### **Dissemination of Results**

The communication of the findings of this study will occur in several ways. Local dissemination of the research findings to health care professionals within Health PEI and the School of Nursing at UPEI will initially occur through oral presentations. Oral presentations will be held at the QEH during grand rounds, and also at UPEI during a nursing research conference. The audience for these presentations will include a variety of health care professionals including nurses, physicians, pharmacists, physiotherapists, and respiratory therapists. This method of dissemination of the findings has the capacity to enlighten the professionals who have direct contact with this population, thereby potentially changing the way they practice. This research study is part of a master's thesis; therefore, a component of the dissemination of the results will be in the format of a thesis. Upon the completion of the thesis, I will write a manuscript to submit for publication in a peer-reviewed nursing journal, with the specific aim to share the research findings, and contribute to the current state of knowledge around the phenomenon. Finally, the research findings will be communicated to the participants who have requested a summary of the findings. Upon the completion of data analysis, a summary will be written of the findings and mailed to the interested participants.

## **Summary**

In this chapter, Giorgi's (2009) phenomenological psychological method was identified as the research method used to guide this inquiry. A description of this method was provided, and participant identification and recruitment approaches described. Study components including the use of a pilot study, data collection plans, study setting, data analysis, ethical considerations, strategies to increase trustworthiness, and dissemination of results were described.

## **Chapter 4**

### **Research Findings**

The purpose of this qualitative study was to explore the family's experience of a loved one's successful treatment with TTM. The researcher sought to answer the question "What is the lived experience of families of patients who have undergone successful TTM after cardiac arrest?" To answer this question, the phenomenological psychological method described by Giorgi (2009) was utilized. To understand the family members' experience of a loved one's treatment with TTM after cardiac arrest, it is important to explore their experience of the cardiac arrest, the time of the treatment with TTM, awaiting the awakening, and the return to life at home after the event. All of these experiences are components of treatment with TTM. Additionally, it was of interest to explore the experiences of family members who had varying relationships to the patient; expanding the sample to include all members of the patient's immediate family increased the richness and depth of the description of the phenomenon. In this chapter, I will discuss the following research findings: (a) demographic data of the participants; (b) descriptive findings obtained from interviews with participants; (c) meaning units that were established through analysis of the participants' descriptions of the experience; and (d) essential constituents that form the structure of the lived experience of families of patients who have undergone successful TTM.

### **Descriptions of Participants**

Nine family members of survivors of cardiac arrest who received treatment with TTM participated in this study. The nine participants were comprised of two men and seven women (see Table 1). Participants' relationship to the patient included wife, husband, sister, sister-in-law, daughter, mother, and father. The age of the participants ranged between 34-69 years, and

Table 1

*Demographics of Participants*

	Relation- ship to patient	Length of relation- ship (if spouse)	Length of time since event	Gender	Age	Present during arrest	Placed call to EMS	Performed CPR
P1	Wife	47 years	3 months	F	65	Y	Unknown	N
P2	Sister-in- law	N/A	14 months	F	71	N	N	N
P3	Wife	45 years	14 months	F	69	N	N	N
P4	Daughter	N/A	14 months	F	41	N	N	N
P5	Husband	34 years	10 months	M	58	Y	N	N
P6	Mother	N/A	24 months	F	47	N	N	N
P7	Mother	N/A	3 months	F	59	Y	N	N
P8	Father	N/A	3 months	M	63	N	N	N
P9	Sister	N/A	3 months	F	34	N	N	N

for spouses, the length of marital relationship to the patient was between 34-47 years. The time elapsed from the cardiac arrest to the time of the interview was between 3 months, and 2 years. Three of the participants were present during their loved one's arrest. None of the participants called emergency services nor performed CPR for their loved one. As recommended by Giorgi (2009), the participant's identity was protected through the use of pseudonyms that include a number. The pseudonyms P1 to P9 were used to describe the participant demographics, and to identify quotes obtained through interviews.

## **Phenomenological Psychological Analysis of Results**

In the following section, the results of the phenomenological psychological analysis are presented and the essential constituents and structure of the phenomenon of a loved one's treatment with TTM after cardiac arrest are identified. During the analysis of the raw data, over 900 large meaning units were identified and these were then transformed into 95 smaller meaning units. Six essential interwoven and sometimes overlapping constituents of the phenomenon emerged from the data and formed the structure of the meaning of a loved one's treatment with TTM after cardiac arrest. These six essential constituents are: (a) a loved one's cardiac arrest and treatment with TTM is an extremely traumatic, stressful, and critical event; (b) waiting for the hoped awakening is a daunting, intensely stressful, and emotionally ambivalent experience; (c) need for constant reassurance; (d) lifelessness to life; (e) family relationship and role adoption; and (f) existential challenges. Each of these constituents are presented along with the associated meaning units (see Table 2). Additionally, direct quotes from participants are provided to enhance the trustworthiness of the study.

### **Typology of the Lived Experience of Families of Patients Undergoing Successful Targeted Temperature Management After Cardiac Arrest**

The six essential constituents of the lived experience of a loved one's successful treatment with TTM after cardiac arrest are identified below with supporting meaning units. Participant quotes are also provided to aid in trustworthiness and to add additional richness to the description of the structure of the phenomenon.



Table 2

*A Typology of the Lived Experience of Families of Patients Undergoing Successful Targeted Temperature Management After Cardiac Arrest*

Constituents	Meaning Units
Constituent 1: A loved one's cardiac arrest and treatment with TTM is an extremely traumatic, stressful, and critical event.	<p>1.1 Participants described how unexpected and stressful it was to receive notification of a loved one's cardiac arrest and they had difficulty absorbing this news.</p> <p>1.2 Participants identified how a loved one's treatment with TTM was an extreme, unusual, chaotic, and unexpected event that left them feeling overwhelmed and in a state of shock and disbelief.</p> <p>1.3 Participants described how anxiety provoking it was to expect and/or witness other family members' distress during a loved one's cardiac arrest, resuscitation, and treatment with TTM.</p> <p>1.4 Participants expressed that the transferring of patients to a larger out of province health centre for specialized services is a demanding, exhausting, and frightening journey for all family members.</p>
Constituent 2: Waiting for the hoped awakening is a daunting, intensely stressful, and emotionally ambivalent experience.	<p>2.1 Participants experienced a loved one's cardiac arrest, resuscitation, and treatment with TTM as a journey entailing both feelings of hope and hopelessness.</p> <p>2.2 Participants described how the experience of a loved one's cardiac arrest and treatment with TTM resulted in significant psychological and physical stress with associated symptoms of de-realization and de-personalization.</p> <p>2.3 Participants described acts of selflessness; concern for their loved-one took precedence over concern for self.</p> <p>2.4 Participants identified that not knowing what had happened to a loved one or what would/could happen was terrifying.</p> <p>2.5 Participants expressed how their loved one's treatment with TTM made them appear lifeless, as though they were dead; they found it extremely difficult to touch them and see them like this, and they feared for the future.</p> <p>2.6 Participants identified how they endured periods of waiting during a loved one's treatment with TTM.</p>
Constituent 3: Need for constant reassurance.	<p>3.1 Participants identified how connections with healthcare providers during the phenomenon was positive and necessary to help them cope with the demands of the experience; a perceived lack of caring from, or trust in, the healthcare provider was distressing.</p> <p>3.2 Participants described how the critical care environment and the actions by healthcare providers had both a positive and negative effect upon the experience of their loved one's cardiac arrest and treatment with TTM.</p>

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Constituent 4: Lifelessness to life.	<p>3.3 Participants expressed how not knowing and/or understanding what was happening made it difficult for them to cope; receiving information helped them cope with their loved one's cardiac arrest and treatment with TTM.</p> <p>3.4 Participants described a need to remain close to their loved one during cardiac arrest, resuscitation, and treatment with TTM.</p> <p>4.1 Participants described how their loved one seemed different and less human during TTM.</p> <p>4.2 Participants described how TTM made their loved one appear lifeless.</p> <p>4.3 Participants identified that the awakening was an amazing and exciting time when they felt relief that their loved one had come back to life.</p> <p>4.4 Participants identified that they felt relief when their loved one became coherent, cognitively aware, and appeared back to themselves after the awakening.</p> <p>4.5 Participants identified that they could envision their lives returning to normal when their loved one became lucid after awakening.</p>
Constituent 5: Family relationship and role adoption.	<p>5.1 Participants considered their role throughout the event to be either one of providing support to family members or directly to the loved one receiving TTM.</p> <p>5.2 Participants who were next of kin described how being asked whether or not to continue with life saving measures was an extremely difficult moral or ethical question.</p>
Constituent 6: Existential challenges.	<p>6.1 Participants described that they gained comfort from God and their faith during times of intense stress, and they also saw God's intervention in the outcome of their loved one's hospitalization; a miracle.</p> <p>6.2 Participants expressed how the experience of a loved one's cardiac arrest, resuscitation, and treatment with TTM was a time when they felt helpless to help their loved one.</p> <p>6.3 Participants described how they couldn't understand why this was happening to their loved one.</p> <p>6.4 Participants described a self-transformation regarding living life after a loved one's successful treatment with TTM.</p>

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### **Constituent 1: A loved one's cardiac arrest and treatment with Targeted**

**Temperature Management is an extremely traumatic, stressful, and critical event.**

*MU 1.1 Participants described how unexpected and stressful it was to receive notification of a loved one's cardiac arrest and they had difficulty absorbing this news. A loved one's cardiac arrest occurred suddenly and unexpectedly during a normal day. When*

participants witnessed this event, or were notified of it by telephone, a feeling of disbelief, shock, and fear engulfed them. P3 expressed this by stating: "... I had talked to him on the phone at 9 o'clock, and this was probably 11 or 11:30, so it was just hard to imagine so much had happened, you know, since I had talked to him. It was scary." P6 described a similar experience in the following narrative: "Um, they called me and I was in complete disbelief because E was completely healthy before that. Had no indications, no signs, nothing." P8 further described the terrible feeling of disbelief he experienced when he was notified of his son's cardiac arrest:

Just... I don't know... It was weird. You find it hard to believe, you know, but I didn't know what to think (crying). What happened? Why was he coming out on the stretcher? What happened? Was he killed? Was he murdered?

***MU 1.2 Participants identified how a loved one's treatment with TTM was an extreme, unusual, chaotic, and unexpected event that left them feeling overwhelmed and in a state of shock and disbelief.*** After family members arrived at the hospital and saw their loved one receiving TTM, this feeling of an incomprehensible reality persisted. P6 described the difficulty she had consolidating her known reality to the reality presented to her during her 17 year-old son's treatment with TTM: "It was like you are so not used to seeing that that it is hard to imagine that is your child lying there unresponsive in that bed. So, it was just hard to piece things together." Similarly, P7 described the shock and disbelief that persisted with her when she was contacting family to inform them of what had happened to her 37 year-old son:

Everybody was like, couldn't believe it and we didn't even really know what to say to them because we couldn't believe it either. It was just so much not said and not told. We just didn't know where we were or how is this possible.

***MU 1.3 Participants described how anxiety provoking it was to expect and/or witness other family member's distress during a loved one's cardiac arrest, resuscitation, and treatment with TTM.*** In addition to the stress felt by participants because of a loved one's cardiac arrest and treatment with TTM, some participants described an additional burden in knowing the distress this would cause other family members or actually witnessing the distress of other family members. P2 describes how difficult it was for her to witness her niece's distress:

It was very difficult. Everybody was very upset and it is very upsetting to see your niece upset, and she is an only child you know. It is very, very upsetting and it was very traumatic I found. I had never gone through that before you know, not with a family member.

This additional perceived stress caused some participants to try to conceal the emotional turmoil that they were experiencing. P3 described her response to seeing her daughter and grandson's distress during her husband's cardiac arrest and treatment with TTM: "It was hard 'cause her and A were just so emotional, but they are emotional people. I guess that I just thought I really can't lose this, I have to hold it together for them."

***MU 1.4 Participants expressed that the transferring of patients to a larger out of province health centre for specialized services is a demanding, exhausting, and frightening journey for all family members.*** In the setting where this study was conducted, patients are required to be transferred to a larger centre approximately 3.5 hours drive away from the local hospital, for advanced cardiac interventions such as angiograms and angioplasty. Participants consistently described the additional burden that this transfer placed upon them. When describing the midnight drive to the larger centre, P3 spoke of her fear for her husband during the

transfer: “I didn’t think A was going to make it. I didn’t think,...I thought we would be stopped half way going to St. John, that the ambulance would be pulled over, that he’d be gone.” In addition to the fear family members endured during their loved one’s transfer to the larger centre, P8 described additional burdens that he faced as a father:

It is very, very difficult and very expensive for a family to pick up and go... like in hotels and travelling over... uprooting and going and living out of a suitcase and not knowing how long you are going to be there. Leaving your children behind, if you’ve got children, you’re leaving your spouse, you know, if you have to go over, it was very difficult. My daughter, she wanted to be there with her brother, but she couldn’t go because she had to look after her own children and S’s so, (crying) that was very hard on her.

**Constituent 2: Waiting for the hoped awakening is a daunting, intensely stressful, and emotionally ambivalent experience.**

*MU 2.1 Participants experienced a loved one’s cardiac arrest, resuscitation, and treatment with Targeted Temperature Management as a journey entailing both feelings of hope and hopelessness.* During a loved one’s cardiac arrest and treatment with TTM, participants frequently experienced hopelessness that their loved one would survive. This is evidenced in the following statement by P2: “I felt that we’re not going to save A. I really felt that. You know I didn’t think that there was much way.” While awaiting her brother’s awakening P9 stated: “I had given up hope at that time.”

In contrast, as time passed, and the patient continued to survive, some participants expressed that feelings of hopelessness transitioned into feelings of hope, specifically when signs of awakening were observed. P3 stated: “You know, as the days kept getting more days, more days we kept... we were more hopeful.” The feeling of hope was further strengthened when

participants recognized signs of their loved one's awakening. P1 described her experience of her husband's awakening: "Well it gave me a lot of hope. It just gave me a lot of hope that he was going to be on this side of the fence and not the other..."

***MU 2.2 Participants described how the experience of a loved one's cardiac arrest and treatment with Targeted Temperature Management resulted in significant psychological and physical stress with associated symptoms of de-realization and de-personalization.*** The experience of a loved one's cardiac arrest and treatment with TTM was intensely stressful and traumatic for participants. This stress was so great, that they experienced symptoms of de-realization, a feeling of unreality and de-personalization, a sensation of being a detached observer of oneself. This is evident in P7's description of her arrival at her son's house after being informed that something terrible was happening there:

And it was just like that is where I entered the dream. K said 'oh my god' and I said 'oh my god, did somebody come in and murder them?' because that is what I thought, why would, what is the commotion? And I jumped out of K's car as she was trying to get it parked and I started running across the lawn and a paramedic was coming out backwards, out the door with a stretcher and at that point I didn't know who was on the stretcher until she got through the door. And it was S and she said 'oh my god I just lost him again' and that is where I went into that whatever. I must have blacked out. I don't know what I did. K grabbed me because they were working on him on his front lawn and I don't even remember how I got into S's house but I don't remember seeing them do anything, so I don't know what happened in that space of where my head went. I can't recall any thing except for in S's living room and L screaming. And there was at that point no ambulance.

They had already left with him. So, I don't know, I lost time in there somewhere because I don't know how I got into S's house...

P6 described a similar experience when she touched her son during his treatment with TTM:

“Uh, we definitely touched him as soon as he came in. Um, we held his hand and we kissed him, um, but yeah it was just weird. It was kind of like an out of body experience.”

In addition to the intense psychological stress that the participants endured during a loved one's cardiac arrest and treatment with TTM, they also described significant physical stress. The following narrative from P4 describes how she felt during her father's treatment with TTM: “I just remember thinking, ‘I am so tired, my head is aching so bad, I'm so worried about my dad...’.” P4 also went on to describe further the physical effect on her, of her father's treatment with TTM after he was transferred to the larger centre a significant distance away:

We stayed at the hotel. We were there for 3 weeks on and off. I came home, I came home I think twice during that time. You can only spend 18 hours at a hospital for so long and then you just are wiped. It is exhausting.

***MU 2.3 Participants described acts of selflessness; concern for their loved-one took precedence over concern for self.*** During a loved one's cardiac arrest and subsequent treatment with TTM, family members described how they put their needs after the needs of their loved one and endured the physical strain that this placed upon them. P2 described the physical strain she endured during the 3.5 hour drive in the middle of the night in order to follow her brother-in-law's ambulance to the larger centre: “Well at one point I was just thinking ‘I hope I can stay awake to get here because I am not used to driving that late at night’.” Similarly, when P7 experienced chest pain during her son's resuscitation, she deflected the nurse's concern because she wanted the healthcare team to remain focused on her son's care:

I had a terrible pain in my chest, terrible. I said to the nurse, 'I feel like I am floating on the top of this room. I have a terrible pain.' and she said 'Oh my god' and I said, 'no no' because I was scared if she came and helped me then they weren't going to help S.

***MU 2.4 Participants identified that not knowing what had happened to a loved one, or what would/ could happen was terrifying.*** Not knowing what had happened to a loved one at the time of the cardiac arrest was extremely frightening for participants. The following narrative from P6 supports this theme: "Horrifying, because he was unconscious and we didn't know at this point what happened." This terrible fear during the period of not knowing persisted with P6 while she awaited her son's arrival, by ambulance, at the hospital. She states in the following narrative, that not knowing was even worse than seeing him so ill:

It was awful because like I said, since you don't know what happened and it was taking so long I just assumed that he didn't regain consciousness on the way to... So it was one of the worst parts, I mean it was bad seeing him, but it was really bad not knowing what had happened in that half an hour period.

The descriptions of how a lack of knowing added to the stress of the experience were repeated with other participants. P5 describes: "It was very difficult because no one knew, uh, what had happened. Like I had a sense but, you know, it was just a guess as to what might've happened." During her brother's treatment with TTM, P9 knew that her questions could not be answered until her brother awoke, or did not wake; this time was very hard for her:

Well it just felt like we just had no, yeah... Everything just felt so unknown, we had so many unknown answers that... And I know there is not a lot that they can tell at that time but maybe just even going through like this is, this is what to expect. Cause that part was frustrating at the time when you are so emotionally drained and you don't have a clue



what is going on and everyone seems to be telling you something different. That was a bit hard as a family member.

***MU 2.5 Participants expressed how their loved one's treatment with Targeted***

***Temperature Management made them appear lifeless, as though they were dead; they found it extremely difficult to touch them and see them like this, and they feared for the future.*** Seeing their loved one undergo TTM and feel so cold was distressing for family members. This theme is supported by the following narrative from P3: "Almost like he wasn't there. You know he was so cold." She goes on to further describe this experience of touching her husband during TTM:

...we felt he was too cold because we would touch him and if we put a blanket over him, an extra blanket, they would come back and then we realized what their purpose was. But it did bother us that he was so cold.

Similarly, P8 expressed how difficult it was for him to touch and see his son receive TTM; the pervasiveness of the concept of death was a persistent component of the experience of TTM.

This is evident in the following narrative from P8:

I don't know. I have never done it before (crying). I never touched a dead body either so, I don't know. I guess that is what it felt like to me. The experience of maybe he felt like a dead body. But again, it didn't, that didn't bother me as much as he was lifeless. That was, that was really bothering me a lot. He was lifeless.

During TTM, P8 also harboured fears for the future of his son and his family. He expressed this in the following description:

I guess I think of too many different things that could happen, might happen. The last thing in the world you really want to do is bury your own child so I guess that was going through my mind time and time again.

***MU 2.6 Participants identified how they endured periods of waiting during a loved one's treatment with Targeted Temperature Management.*** Because it cannot be predicted if the patient will survive or not until he/she either awakens, or remains comatose, participants felt as though time moved very slowly when they were anxiously waiting for the awakening. P9 describes this experience in the following narrative:

Oh it was awful. We were all very upset and it is just, it's hard and I know they can't give you any, it's just hard being on the other end of things and not knowing anything really until this cooling process is over.

She goes on to further describe the experience of waiting for her brother to awaken: "When you are waiting that every second of hope that you are close to the end, it just seems like forever."

The waiting that participants endured during a loved one's TTM was acutely intense for participants; P1 referred to it as *the wait* and could still recall the exact time that her husband's TTM began, and then when the rewarming period began: "...they would bring his body temperature down close to 32 and leave him like that for 24 hours, which they did. So then the wait started at around 4 o'clock."

### **Constituent 3: Need for constant reassurance.**

***MU 3.1 Participants identified how connections with healthcare providers during the phenomenon was positive and necessary to help them cope with the demands of the experience; a perceived lack of caring from, or trust in, the healthcare provider was distressing.***

Participants expressed a need to have contact with the staff members who were caring for their loved one during resuscitation and treatment with TTM. The lack of contact had a negative effect on participants. P7 describes her experience when staff members were caring for her son and she was in the waiting room in the hospital:

the nurses never, they came out of that trauma room, and maybe they can't come out of that trauma room, I don't know, but they never came out into the other room to see if we were alright... it just felt that he was... and we were, more alone in trauma.

Conversely P6 describes the experience that she had when her son was receiving his treatment with TTM:

...he had like nurses around him 24/7 and, you know, they were working on him and checking his machines and comforting me and telling me he is fine and he is stable right now. And, you know, it felt really good.

***MU 3.2 Participants described how the critical care environment and the actions by healthcare providers had both a positive and negative effect upon the experience of their loved one's cardiac arrest and treatment with Targeted Temperature Management.*** During a loved one's treatment with TTM, elements of the critical care environment were an additional stressor for participants. For example, P7 describes how she felt when she saw her son receiving TTM:

Well I could see that my son was naked with his hands tied down by his sides. It was just so inhumane looking. And then when I touched his arm, I mean it's mental and visual... Mentally I understand it but visually I don't really want to see that.

P4 had a similar experience with the critical care environment when she visited her father for the first time in ICU:

So we went right in and he had even... I was scared again, I was scared to go near him honestly because he had even more lines coming out of him and machines hooked up and beeping, and all these monitors and stuff.

Similarly to the effect the critical care environment had upon family members' experiences, behaviours and actions by healthcare staff can also have a very positive or very negative effect on

their experience. For example, P6 recalled how the behaviours and actions of staff caring for her son gave her comfort during her son's treatment with TTM:

Very cool and calm and collected. Like we see this every day kind of thing... Kind of like, you know, he is a patient here just like everybody else, nobody is freaking out, we have got this under control. Yeah, it was great.

P9 also described the positive effect healthcare staff behaviour had on her when she described the experience of not knowing what the future held for her brother: "They were fantastic with, you know, keeping us involved and letting us be there at the bedside, which means the world right 'cause you don't know where you are heading." However, P5 describes an experience he had during his wife's treatment with TTM that was extremely upsetting for him:

There was a snow storm on a Saturday evening and she had to come, in and she was very abrupt with everybody. I tried to kinda calm her down because she was going on and on about her employer and having to come in, in a storm like this, and why couldn't they get somebody else, and also the thing is she had to take care of my wife... it was just terrible.

***MU 3.3 Participants expressed how not knowing or understanding what was happening made it difficult for them to cope; receiving information helped them cope with their loved one's cardiac arrest and treatment with Targeted Temperature Management.*** The distress participants experienced when they experienced a lack of knowledge or understanding around what was happening to their loved one was a frequently repeated theme. P6 describes her experience while she awaited her son's arrival by ambulance at the hospital: "...you can deal with it if you know so the not knowing you just start to go crazy and think crazy things."

The intrinsic unknown that accompanies TTM was very difficult for family members to endure. P9 describes how she felt:

Everything just felt so unknown, we had so many unknown answers that... And I know there is not a lot that they can tell at that time but maybe just even going through like this is, this is what to expect. Cause that part was frustrating at the time when you are so emotionally drained and you don't have a clue what is going on and everyone seems to be telling you something different. That was a bit hard as a family member.

***MU 3.4 Participants described a need to remain close to their loved one during cardiac arrest, resuscitation, and treatment with Targeted Temperature Management.*** Remaining close to their loved one during their cardiac arrest and treatment with TTM was reassuring for participants. The following narrative from P5 supports this: "...in the waiting area but it was like I was there and I wasn't very far away. It gave me a really, a sense of consolation that if anything took place that she wasn't going to be alone." This need to remain close was also present when the decision was made to transfer patients to a larger centre a significant distance away. P6 describes her need to remain close to her son during his transfer:

Well, I mean, like I said, I wanted to be with him, you know, the whole time just in case he did wake up I wanted to be there because I knew he would have questions....To know that I would have had to drive three and a half hours would have been awful. I just wanted to be there with him. So, I was really relieved when I was able to go.

#### **Constituent 4: Lifelessness to life.**

***MU 4.1 Participants described how their loved one seemed different, and less human during Targeted Temperature Management.*** During a loved one's treatment with TTM, family members described how their loved one seemed different, like they weren't there. P1 describes this experience in the following narrative: "...the most I probably would have stayed in the room at one time maybe would be a half an hour. I just, I almost felt like he wasn't there, that it was

just his body.” Further to this perception, participants described how their loved one almost seemed to no longer be human; rather they were felt to be more like an object during treatment with TTM. A narrative of P7 who was describing how her son appeared during TTM supports this theme:

“He’s not got pyjamas on, he is just a form under this cold object.” This experience was similar for P4 when describing how her father appeared during TTM: “I remembered that they had packed him in ice before we left...”

***MU 4.2 Participants described how Targeted Temperature Management made their loved one appear lifeless.*** During a loved one’s treatment with TTM, participants perceived that he/she appeared to be lifeless, dead; this was intensely stressful for them. A narrative by P7 supports this theme:

It is pretty traumatic seeing somebody under a sheet of ice. It is not a sheet of ice, but it is a sheet of ice. It is a blanket of ice. ... I see my child under a sheet and his body feels like a dead person and it is just like, it’s like stark reality. It was pretty shocking...

The concept of death was frequently repeated in participants’ recollections of their loved one’s treatment with TTM. This was reflected in P8’s description of his son’s treatment with TTM:

...you go to a wake or you go to a funeral and it is a young person and, you know, you say you’re sorry but we don’t really understand what those people are going through and now I have a good idea of what they go through because it felt like being at a funeral for three days.

Similarly, P9 revealed the following experience of her brother’s treatment with TTM: “He looked dead (crying). He felt cold. He had so many tubes. Um, yeah...Just you wonder is he hearing you. He just looked lifeless.”

***MU 4.3 Participants identified that the awakening was an amazing and exciting time when they felt relief that their loved one had come back to life.*** Although the concept of death surrounded participants' experience of a loved one's treatment with TTM, the period of rewarming was associated with their loved one coming back to life. This is supported in the narrative of P8:

Well just holding his arm, his arm was getting warmer and his hands were getting warmer. It was just like, I can't even remember the movie but there was movie where somebody died and came back to life, I know that is far fetched but, you know, he was sucked out of the body in terms of the feeling, the sense of, you know, touch the warmth of a person's body and then it goes cold, but he was getting warmer, and warmer, and warmer, and it was just like life was coming back into him.

A loved one's return to life was an exciting time for participants. P9 describes this moment of awakening in an excited and emotional tone of voice: "...and it was like two hours later and the phone rang. And they were like, 'Your brother is talking'. It was like the most craziest feeling in the world." This experience was supported by P6's description of the moment of her son's awakening: "...I said, you know, 'can you hear me' and 'if you can, squeeze my hand' and he did. And so that was really exciting, you know, to know that he is coming around..."

***MU 4.4 Participants identified that they felt relief when their loved one became coherent, cognitively aware, and appeared back to themselves after the awakening.*** When patients initially awoke after TTM, they often experienced a period of time when they were confused. However, as this confusion resolved, participants recognized the moment when they perceived that their loved one was back. P7 describes the moment when she recognized that her son did not suffer a neurologic injury, and he was back to himself: "It's like ahh he is back. He is

back. I knew... I could see it.” Similarly, P9 described the moment when she recognized that her brother was back to himself after his awakening two days previous:

Um, I think it was Sunday I got a text from him to say like how thankful he was, taking care of the boys and how much he missed everyone and I was like oh my gosh he is back. He makes sense now. So that was amazing.

This theme is also supported by the following narrative by P1 when she felt her husband had returned to the way he was on the morning of his cardiac arrest: “...he just mouthed the words “I love you”... I guess I felt when he was able to do that, that he was going to be coming back the way he was when he woke up that morning.”

***MU 4.5 Participants identified that they could envision their lives returning to normal when their loved one became lucid after awakening.*** When family members experienced the turning point when they recognized that their loved one was back, they could then envision their lives returning to normal. P4 describes in the following narrative how her father’s comments enabled her to see life coming back to normal:

...Is that your coffee?’ he said to the nurse ... and she said, ‘Yeah, yeah that’s my coffee’ and dad said, ‘I’ll give you 20 bucks for it.’ I almost fell into a pile on the floor because dad loves Tim Horton’s coffee and that was so much like something dad would say.

P8 also described a similar experience when his son’s lucidness was improving: “So, and, as time progressed and S said some funny things and, he just, he was just back to his normal S.”

#### **Constituent 5: Family relationship and role adoption.**

***MU 5.1 Participants considered their role throughout the event to be either one of providing support to family members or directly to the loved one receiving Targeted Temperature Management.*** Sisters to the loved one who was undergoing TTM, saw their role in



the experience as one of support for other family members. P9 describes what her focus was during her brother's treatment with TTM: "I felt like I kept strong all week for everyone else and then I think I was just done." This was also supported by a statement P2 provided when she was asked what she felt her role to be during the experience: "Support. You know I was there just to support..."

Not only did family members aim to support other family members during the experience, mothers aimed to help their children who were patients. When P6 was asked why she wanted to remain close to her son during his transport to the larger centre, she responded: "I wanted to be there because I knew he would have questions... And I just, I just had that motherly instinct to be there when he woke up."

***MU 5.2 Participants who were next of kin described how being asked whether or not to continue with life saving measures was an extremely difficult moral or ethical question.***

Family members who are identified as the patient's next of kin may suffer the additional burden of decision maker during the event. P3 described the burden she was made to bear when the physician asked her if she wanted him to continue her husband's resuscitation, or stop:

...then they did ask me, ... did I want them to stop because he had arrested so many times. I said 'No'. At the back of my mind I'm thinking, you know, this has happened so many times, I have a little background, what if he doesn't come back or what if he comes back in a vegetative state, he would be so upset. But it was such a hard call to make.

#### **Constituent 6: Existential challenges.**

***MU 6.1 Participants described that they gained comfort from God and their faith during times of intense stress, and they also saw God's intervention in the outcome of their loved one's hospitalization; a miracle.*** Participants described how their faith in God gave them a

sense of comfort during an intensely stressful time. P1 described how she handed over the fate of her husband to God while she was making her way to the hospital after her husband's arrest:

Then I just, I've got great faith, and I just told the lord that this was going to be his, it was much bigger than me and I couldn't do anything about it. I know some people think that both C and I are crazy for this but I was scared but I had peace at the same time.

P8 also gained comfort when a priest anointed his son, and he also experienced a comforting physical sensation:

I felt um, that he was going to make it when Father G prayed with the family the night it happened. I felt a very warm feeling over my body when he said the prayers. He had gone in, he had anointed him and come back and just the calmness of his face and the prayers that he shared with us gave me a real sense of comfort.

Some participants did not describe God as having a role in their loved one's survival. However, they describe their loved one's survival as a result of something beyond the realm of normal, or expected. An example of this is demonstrated in the following narrative from P2: "Like I think it was a miracle actually, that's how I look at A. Like he is alive today because of a miracle."

***MU 6.2 Participants expressed how the experience of a loved one's cardiac arrest, resuscitation, and treatment with Targeted Temperature Management was a time when they felt helpless to help their loved one.*** Although the participants were desperate to help their loved one during treatment with TTM, they felt powerless to do so. This is evident in the following narrative from P7 when she was describing her son's awakening: "It was bittersweet because my heart was broken because I couldn't help him and I couldn't tell him because he didn't understand..." Similarly, P9 describes a sensation of a loss of control in her ability to help her

brother during his cardiac arrest: “And I felt very out of control. You know what I mean? Like there was nothing I could do, just sit back and watch it all unfold. So it was hard.”

***MU 6.3 Participants described how they couldn’t understand why this was happening to their loved one.*** Participants searched for a reason that this was happening to their loved one, but they were unable to find a reason. This is explicit in the following narrative from P6 when she was considering her son’s situation during TTM:

And, uh, you know, you had this healthy kid that to me at that point, had no knowledge of him doing drugs or drinking or anything and was a good responsible kid and you know, he did nothing to end up in this situation.

P9 described a similar experience when she received notification of her brother’s cardiac arrest by telephone:

My heart just sunk and it was unbelievable I guess. You don’t think that your 37-year-old brother is going to go into cardiac arrest. It’s just not something you picture, you imagine, I know it happens but I guess you just never think you’re going to be there.

***MU 6.4 Participants described a self-transformation regarding living life after a loved one’s successful treatment with Targeted Temperature Management.*** Once their loved one was discharged from hospital, participants described a persistent fear that their loved one would suffer a recurrence of cardiac arrest and die when the participant was not with them. P1 described how she fears a recurrence for her husband:

So I guess in the back of my mind. So I left him there today and all is well. It’s not leaving him so much it’s coming home and there is dead silence in the house. Is he sleeping or is he on the floor?

P3 described a similar fear of her husband becoming unwell again and being alone when she returned to work: “I was worrying, you know, but I felt after what he had been through, the least little twinge he would have he would be up on the phone to me telling me, ‘I’m having pain’.”

After a loved one’s survival from cardiac arrest and treatment with TTM, participants identified that the experience changed them in a way they perceived as positive. The following narrative from P7 supports this theme: “Yeah, it is like our life has been changed. Don’t worry about money so much now, it’s like it will all work out, it all works out.” Similarly, P8 feels the experience of his son’s cardiac arrest and treatment with TTM has had a caused a positive change for his family:

Yeah. I am more thankful for the things that we have, for what I have. For the family, for friends... I mean it has brought us closer. Now I hope that doesn’t fade away ... it seems so much more cohesive now than it was before.

Additionally, some participants described an increased awareness of mortality. This is evident in the following narrative from P3:

I’m sure it has changed for me, you know, because in the flash of an eye, the blink of an eye, he could have been gone, and you know, he is back with us which is wonderful. Yes, I guess maybe I don’t take things for granted.

### **Summary**

In this chapter I presented the family members’ lived experience of a loved one’s treatment with TTM after cardiac arrest. Demographics of the participants were described and the six essential constituents of this phenomenon presented. I used Giorgi’s (2009) phenomenological psychological method to reveal these essences. In this study, participants described their experience of a loved one’s cardiac arrest and treatment with TTM to be: (a) an

extremely traumatic and critical event that provokes existential challenges; (b) a time when constant reassurance is sought and a lack of reassurance negatively affects coping; (c) waiting for the hoped awakening was a daunting, and intensely stressful experience; (d) during rewarming, a loved one is perceived to transition from lifelessness to life; (e) a turning point is experienced when the loved one becomes lucid; (f) the experience results in self-transformation regarding living life; and (g) the degree of familial relationship directly affects role adoption and perceived intensity of the experience. These findings will now be discussed in the context of our current knowledge of this phenomenon.

## **CHAPTER 5**

### **Discussion**

The purpose of this qualitative study was to explore the family's experience of a loved one's successful treatment with TTM. Giorgi's (2009) phenomenological psychological research method was utilized to reveal the essential elements of this phenomenon. In this chapter, a summary of the findings will be presented and the constituents of the phenomenon will be discussed within the context of the existing literature.

By using Giorgi's (2009) phenomenological psychological method, the essential constituents that form the structure of the experience of a loved one's successful treatment with TTM after cardiac arrest were revealed. Nine participants were interviewed and their relationship to the patient was one of either mother, father, wife, husband, sister, or sister-in-law. Participants were predominately female, and the duration of time from the event to the interview was between 2 months to 2 years. All of the participants willingly described their experience related to their loved one's cardiac arrest and subsequent successful treatment with TTM.

The essential constituents that form the structure of the experience of a loved one's successful treatment with TTM after cardiac arrest are interconnected and overlapping. This experience was intensely stressful for family members and they constantly sought reassurance from within the self and from numerous sources outside of themselves. The concept of death was pervasive throughout the participants' descriptions of their loved one's treatment with TTM; the loved one looked and felt like death. Upon completion of TTM, the time awaiting the hoped for awakening was daunting and intensely stressful; some participants described this as the most difficult time to endure. During the rewarming period, participants described their loved one as transitioning back to life after a period of lifelessness. Once their loved one awoke, participants

described a turning point when their loved ones became lucid and seemed to be back to themselves after a period of disorientation upon awakening. New knowledge around this phenomenon was revealed including the provocation of existential challenges felt by family members, differences in perceived realities that are dependent upon family roles, and the additional emotional, psychological, and financial burden that family members experienced when their loved one was transferred to another centre a significant distance away for ongoing treatment after TTM. All participants identified that the experience of a loved one's cardiac arrest and subsequent treatment with TTM left them feeling changed by the event.

### **A Loved One's Cardiac Arrest and Treatment with Targeted Temperature Management is an Extremely Traumatic, Stressful, and Critical Event**

Participants described how their loved one's cardiac arrest occurred suddenly and unexpectedly and they felt overwhelmed, in a state of disbelief and chaos, and felt as though the situation was unreal. Participants who were not present for their loved one's cardiac arrest found it extremely difficult to absorb information about the event, and one participant even thought she had received a prank phone call until the paramedic spoke directly with her. This finding supports previous studies that have revealed the family members' experience of a loved one's cardiac arrest to be an unexpected, frightening, and dramatic event that feels unreal; receiving notification by telephone of a loved one's cardiac arrest is a shocking, chaotic and shattering experience for family members (Holm et al., 2012; Larsson et al., 2013; Löf et al., 2010). Being present and directly witnessing a loved one's cardiac arrest has been described as unreal and hard to understand (Ann-Britt et al., 2010; Bremer et al., 2009; Weslien et al., 2005). Similarly, in the current study, seeing their loved one receive TTM after a successful resuscitation was shocking for family members and they had trouble consolidating what they knew of their loved one before

the event, with what they saw happening to their loved one during TTM. Family members continued to describe this state of shock during their loved one's treatment with TTM and had difficulty telling other family members what had happened to their loved one because they had difficulty understanding the situation themselves. My study adds support to the finding by Löf et al. who described the family members' perception of a loved one's treatment with TTM to be an incomprehensible experience that left them feeling an inner chaos.

My study also revealed how the expectation or witnessing of other family members' distress over the situation was anxiety provoking for some participants. Several participants described how traumatic it was for them to see their immediate family members so upset and visibly suffering during their loved one's cardiac arrest and treatment with TTM. Participants also described how they worried about their immediate family members becoming upset when they received the news, and several participants worried about their loved one feeling frightened, upset, or cold during their treatment with TTM. To assist others, participants described how they tried to hold themselves together for the sake of other members of their family. They described this action not as a burden for them, but rather something they wished to do to support their family members. This finding expands our current knowledge of this phenomenon. In the TTM literature, this is only noted in the study by Larsson et al. (2013) who identified that family members found it challenging to see other family members distressed during a loved one's cardiac arrest and treatment with TTM, and they found it difficult and demanding to deal with other family members' worries. In the general critical care literature, Turner-Cobb, Smith, Ramchandani, Begen, and Padkin (2016) found that family members experience a need to manage the emotional responses of other family members when a loved one was critically ill. Engström and Söderberg (2004) also reported in their descriptive study that partners of critically



ill patients worried about how other family members would cope. To date, no other studies have revealed this experience of family members during a loved one's cardiac arrest and treatment with TTM.

When compared to the previous literature, a novel finding emerged in my study. Participants described an additional psychological, emotional, physical, and financial burden that was placed upon them when their loved one was transferred to a larger centre a significant distance away for ongoing advanced care and interventions. Family members described how the thought of being separated from their loved one during the transfer was “awful,” and others described the fear and physical exhaustion they experienced during a long overnight drive behind their loved one's ambulance to a remote, urban hospital in New Brunswick. A similar finding was described in a study conducted by Masterson and Brenner (2016), who identified that parents who were not allowed to travel with their critically ill child experienced increased anxiety and stress during this experience. Participants in my study also described how tiring it was to constantly be at the bedside in an unfamiliar hospital and to stay at a hotel for several days, or even weeks.

In an attempt to support other family members, some participants described how they stayed at home to care for young children. Moreover, others participants took on additional family responsibilities while other family members went to the larger centre to be with their loved one who was receiving ongoing care. In this situation, one participant described how difficult it was to watch her loved one and other family members travel to the larger centre and not be able to follow them. Previous research also described how a loved one's inter-hospital transfer during critical illness caused family members to feel concern, stress, confusion, and disorientation when they were required to move to an unfamiliar environment with less support.

Consequently, this situation could lead to a decline in the health status of the family members (Mackie, Kellett, Mitchell, & Tonge, 2014). Participants in my study also described the financial burden they were made to bear with their loved one's transfer to a different facility. For example, one participant estimated that it cost his family approximately \$2000 to be at the larger centre with his loved one for 5 days of treatment. This finding was consistent with other studies that identified the financial burden that is borne by family members of critically ill patients who require inter-hospital transfers (Mackie et al., 2014; Mohr, Harland, Shane, Miller, & Torner, 2016).

### **Waiting for the Hoped Awakening is a Daunting, Intensely Stressful, and Emotionally Ambivalent Experience**

The intensely stressful and emotionally ambivalent experience of waiting for a loved one's hoped for awakening was persistently described by participants from the moment of their loved one's cardiac arrest until he or she awoke, was coherent, and was cognitively intact. During this time, participants identified that they hoped their loved one would survive, but also felt that it was a hopeless situation and they could not see how their loved one could survive this event. Although feelings of hope and hopelessness are described in the study by Holm et al. (2012), other TTM studies did not note the concept of hopelessness in the context of this phenomenon. Larsson et al. (2013) indicated in their study that although family members were uncertain about their loved one's future, they still felt hopeful that he or she would survive. Similarly, Löf et al. (2010) found that participants had a persistent feeling of hope, not hopelessness, that their loved one would recover and have a good future. In studies conducted outside of the context of TTM, family members describe alternating between feelings of despair

and feelings of hope during a loved one's critical illness (Engström, & Söderberg, 2004; McKiernan & McCarthy, 2010).

Participants described the intense stress that they experienced while their loved one was receiving resuscitative measures during cardiac arrest, and also during the time of treatment with TTM. Participants verbalized how their loved one's cardiac arrest and subsequent resuscitation was a dark and devastating time when they frantically sought help for their loved one; they felt unable to leave their loved one's side and feared that their loved one would not be resuscitated. This experience was so intensely stressful for family members, that some participants described symptoms of de-realization and de-personalization such as: having feelings of unreality, being surrounded by a fog, a feeling of separation from the body, floating on top of the room, and watching the resuscitation as if it were a show.

After the resuscitation event, family members also described the treatment with TTM as an intensely stressful time. Participants described how extremely distressing and traumatic it was to see their loved one under what was perceived to be a sheet of ice, feeling cold to touch, lifeless, and dead. The stress of the loved one's treatment with TTM manifested as physical symptoms for some family members. These symptoms included exhaustion, terrible chest pain, and physically collapsing at the bedside. Additionally, vivid memories of the stressful nature of this experience persisted long after the event for participants. Memories of the event elicited a physiologic response during the interviews; participants flushed and became visibly upset when recounting an event that in some cases occurred up to 2 years previously. These findings support work from previous researchers. In a study conducted by Löf et al. (2010), family members described the event of a loved one's cardiac arrest as a time when they felt agitated, shocked, and afraid. Larsson et al. (2013) and Holm et al. (2012) also had similar findings in their studies;

participants described a loved one's cardiac arrest as a time when they experienced panic, fear, desperation, anxiety, and dark thoughts. Although symptoms of de-realization and de-personalization were described by a number of participants in the current study, these experiences did not feature as prominently in previous research. In the study by Larsson et al., the experience of de-realization was briefly noted when the authors identified that relatives experienced a sense of unreality during a loved one's resuscitation from cardiac arrest. As with the current study, previous research identified that it is difficult, frightening, and traumatic for family members to see a loved one receiving TTM (Holm et al., 2012; Larsson et al., 2013; Löf et al., 2010).

The theme of selflessness or self-neglect was repeated by participants throughout the interviews. They described how they denied their own needs for rest or comfort so that they could be present as a resource for their loved one who suffered the cardiac arrest and also for other family members. One participant described how she experienced terrible chest pain during the initial stages of her son's treatment with TTM, and when a nurse offered to help her, she refused this help because she wished for the nurse to concentrate solely upon her son's care. In the general critical care literature, Agård and Harder (2007) also found that family members placed their needs second to their critically ill loved one, and in an effort to keep the team's focus on their loved one, they attempted to draw as little attention as possible to themselves. Weslien et al. (2005) and Engström and Söderberg (2004) identified similar behaviours of selflessness among family members during a loved one's cardiac arrest. When considering the current literature that explores the family members' experiences of selflessness during a loved one's TTM, there is limited knowledge noted. A similar finding was not described in the studies by Holm et al. (2012) or Larsson et al. (2013), but was identified as a key category in the study

by Löf et al. (2010) where participants described how they put themselves second and directed all of their energy toward their loved one. However, it was not reported whether participants also put themselves second with regard to supporting other family members (Löf et al. 2010); hence, the current study adds to our current understanding of this theme.

Previous studies have found that relatives perceived a loved one's treatment with TTM to be a time of waiting in uncertainty and fear for the future, which evoked feelings of anxiety (Larsson et al., 2013; Löf et al., 2010). These findings are consistent with the findings of the current study. Participants described how not knowing what had happened to their loved one, or what would happen to their loved one as challenging, frustrating, and terrifying. One participant described how not knowing made her feel crazy, and was in fact worse than seeing her son so ill. Conversely, receiving information provided participants with great comfort and reassurance during this difficult experience. Larsson et al. also found that the family members' need for information was connected to their feelings of security in the difficult situation of a loved one's treatment with TTM.

Death was a pervasive concept that was interwoven throughout participants' experience of a loved one's treatment with TTM. Family members described how seeing their loved one receiving TTM was distressing, and it was hard for some participants to be near their loved one during this time. Their loved one appeared lifeless during treatment with TTM, and felt cold and like death when they touched them. One participant described how his son looked like a dead body, and the time of his son's treatment with TTM felt like he was at a funeral for 3 days. During this time, participants feared for the future; would their loved one survive, or would they survive but be left with brain damage? Larsson et al. (2013) and Löf et al. (2010) noted similar findings in their studies. However, Holm et al. (2012) found that partners of patients who were

receiving TTM did not describe the cold body as traumatic but as a part of the care and accepted it as such.

Participants described how they endured the time of awaiting their loved one's awakening. This time felt prolonged and was horrible for them. One participant described the rewarming period as the worst day of the entire experience because she feared that her loved one had suffered a serious neurologic insult. Similarly, Holm et al. (2012) found that family members experienced the anticipation on the awakening as a time of constant suspense and the worst part of the entire treatment.

### **Need for Constant Reassurance**

In the current study, constant reassurance was sought during a loved one's cardiac arrest and treatment with TTM; a lack of reassurance negatively affected coping. Participants looked for reassurance during their loved one's cardiac arrest and treatment with TTM in numerous ways and from numerous sources. They sought to have connections with both nurses and physicians; they perceived these connections as positive; and they helped them cope with the experience. During a loved one's resuscitation, frequent updates from staff was felt to be wonderful and supportive. Physical demonstrations of caring connections from healthcare providers to participants, such as hugging them, or coming out of the operating room to speak directly with family members, was also perceived as positive. Conversely, a lack of perceived connection with the healthcare team was distressing for participants. While waiting for his son to arrive at the hospital after suffering a cardiac arrest, one participant described how staff did not seem to know what was going on and he perceived this to mean that they did not care about his son or his family. This made the participant feel alone during this experience. Previous findings have briefly described how family member connections with healthcare staff were

positive and beneficial for these family members. Löf et al. (2010) identified that family members felt a feeling of safety when healthcare providers made them feel welcome at the patient's bedside. However, Larsson et al. (2013) found that the family members' experience of support from the healthcare team varied and then lessened when the patient was transferred out of the critical care area to the general ward.

Participants in the current study reported mixed experiences with regard to their exposure to the healthcare environment. The healthcare environment is more than simply the physical surroundings contained within the critical care environment. Rather, the environment also includes non-physical components such as the organizational structure, and critical care policies, procedures, and protocols. When exposed to the healthcare environment, some participants described how the unfamiliar environment with the associated equipment and noises was very frightening. Another participant described how the TTM protocols of ICU were very distressing for her; she described how inhumane it was to see her son tied down with a sheet of ice on top of him. Conversely, another participant described how she felt comforted with seeing the critical care staff checking her son's life support equipment and in knowing that her local hospital had the appropriate equipment to care for her son. Previous research has revealed similar results. Although Larsson et al. (2013) found that family members perceived the critical care environment to be frightening, Löf et al. (2010) identified that family members found the ICU environment to be peaceful, and the medical equipment inspired a feeling of safety. Holm et al. (2012) had mixed results in their study; family members perceived the environment to be either comforting or frightening.

As with the positive and negative effects of the healthcare environment on the family member's experience of a loved one's treatment with cardiac arrest, actions by healthcare

providers also had both a positive and negative effect. Several participants indicated that witnessing highly skilled, knowledgeable, confident, and professional healthcare providers caring for their loved one provided great comfort to them. Optimistic healthcare providers and frequent updates from these providers gave comfort and reassurance to family members. One participant described how witnessing a healthcare staff member crying at her son's bedside after his resuscitation made her feel good because she then appreciated how compassionate the staff was. This finding supports the study by Wong et al. (2015) who found that family members felt supported when healthcare providers provided reassurance and responded to their non-verbal cues. The benefits of these positive interactions with healthcare providers are echoed by Titler et al. (1995) who identify that once the family's reassurance needs are met during a loved one's critical illness, they are then able to focus upon their own support needs.

Conversely, a participant in the current study described how interactions with healthcare staff made him feel that they were very detached and self-absorbed; this was an additional stressor for him because of his wife's vulnerability and his associated fear for the care this particular healthcare provider would give his wife. These findings are also supported in the general critical care literature. In a study set in a medical ICU by Khalaila (2013), family members identified a need for information and reassurance from ICU staff. However, these needs were insufficiently met. Wong et al. (2015) found that family members felt unsupported when healthcare professionals spoke abruptly or rudely to them, or provided them with inconsistent information. Concerning the specific population of family members of patients who survive cardiac arrest and subsequent treatment with TTM, the effect of the healthcare providers' actions upon the family members' experience is not well described in the literature. In the study by Holm et al. (2012), family members described healthcare providers as professional and



answered their loved one's alarms quickly and explained their actions to family members. Moreover, Löf et al. (2010) described that family members felt safe when healthcare staff noticed changes in their loved one and addressed these changes quickly. However, in Larsson et al.'s (2013) study, the authors found that the family members' experience of support from healthcare providers varied for each participant.

Not knowing and/or understanding what was happening to their loved one was described as very distressing and frustrating for participants of the current study. Participants indicated that if they had received information about the rationale of TTM, they might have been more accepting of it. One participant stated that when he understood the rationale for TTM, he then perceived it to be a logical treatment for his son. Some participants perceived the lack of updates from staff as adding to the stress of the situation for them; this finding is supported the existing literature. Azoulay et al. (2005) argue for a need to improve communication between healthcare providers and family members of critically ill patients because a perceived incompleteness of shared information is associated with the family members' development of post-traumatic stress reaction. In contrast, participants in the current study described feelings of relief and comfort when they received information and updates from staff about their loved one. This finding is consistent with what is described in the literature. Löf et al. (2010) found that receiving ongoing information from staff was reassuring and important for family members. The family members' need for honest and realistic information was also a theme in the study by Holm et al. (2012).

During a loved one's cardiac arrest and subsequent treatment with TTM, family members described their need to remain close to their loved one. During the patient's transfer to a larger centre, family members identified that it would be horrible to be parted from their loved one. Therefore, they remained close to their loved one by travelling closely behind the ambulance or

flying with them in the Medevac helicopter. Other participants described how they remained in the patient's room or in the hospital waiting room during their loved one's treatment with TTM rather than returning to their home or hotel room. Interestingly, although this need to be close to the patient during TTM was a persistent theme in the current study, it is only briefly mentioned in the literature. Holm et al. (2012) identified that family members experienced a strong need to remain close to their loved one during the time of the anticipated awakening, more so than during the time of TTM.

### **Lifelessness to Life**

During rewarming, a loved one was felt to transition from lifelessness to life and the turning point toward recovery occurred when a loved one became lucid. Participants in the current study described how their loved one appeared different during their treatment with TTM. Family members perceived them to be less human and sometimes spoke about their loved one as if they were objects during the treatment. One participant described how her son appeared to be just a form under the cooling blanket. Another participant described how her father was packed in ice before he was transferred to another centre for continued treatment. Although one study found that family members perceived their loved one to be changed during treatment with TTM (Löf et al., 2010), the unconscious objectification and dehumanization of the patient receiving TTM by family members has not previously been described in the literature. This may indicate that participants in the present study noted such a significant change in their loved one during TTM and that they did not even appear to be human anymore.

During a loved one's treatment with TTM, participants described how their loved one appeared devoid of life. Some participants described that their loved one felt so cold, it was almost like they were not there at all. Other family members described their loved one as feeling

so cold and dead that they seemed to be lifeless during the treatment with TTM; some participants found this so distressing that they were unable to stay at their loved one's bedside for more than short periods of time. This finding is well supported in previous studies. Löf et al. (2010) and Larsson et al. (2013) describe how family members perceived their loved one to appear lifeless and dead during treatment with TTM. Löf et al. and Larsson et al. also described how distressing this was for family members of these patients.

A loved one's awakening after treatment with TTM was described by participants as an exciting time when they felt as though their loved one had returned to life. The rewarming period was described as life gradually returning to the loved one as they progressively warmed to the family member's touch. Family members described the awakening as a time when the family moved from sitting in silence in the waiting room to noisy excitement when signs of the awakening began. One participant described his intense excitement when his son first opened his eyes and squeezed his hand. Some patients remained confused when they first awoke and this was a concern for family members. However, when the loved one eventually became coherent and appeared to be cognitively intact, family members perceived a turning point and felt great relief that their loved one was back. With this lucidity and return to self, family members described how they could envision their lives returning to normal which brought them great relief. These experiences have also been repeated in the existing literature. Family members felt joy and relief when their loved one awakened and recognized them (Holm et al., 2012; Löf et al., 2010), and as they became more alert and coherent, family members felt more hopeful about the future (Löf et al., 2010).

## **Family Relationship and Role Adoption**

In the current study, the degree of familial relationship directly affected role adoption and the perceived intensity of the experience. There is limited description in previous research that addresses the effect of familial connection to the loved one receiving TTM and role perception or adoption during the event. By including partners, siblings, children, and parents in the current study, the researcher sought to expand the current understanding of this relationship. In this study, participants who were siblings to the patient receiving TTM considered their role to be one of supporting other family members during the event. These participants provided support to other family members by assisting with transportation needs, childcare, and acting as a ‘pillar of strength’ for others to lean on. Spouses of these patients perceived their role to be one of caregiver and support person to their adult children, and collaborator with the healthcare team when making healthcare decisions. These spouses were also identified by the healthcare team as the next of kin of the patient receiving resuscitative measures and subsequent treatment with TTM.

Participants who functioned as the next of kin were asked for direction from the healthcare team regarding whether to continue resuscitative efforts for their loved one, or to discontinue these efforts and accept their loved one’s death. This responsibility was perceived to be very difficult and challenging for these participants. Parents of patients who received TTM perceived their role to be one of supporting all members of their family including their child both during and after successful treatment with TTM. The participant who was a child of a patient receiving TTM described how she was not strong enough to endure this experience without the support of her family; therefore her role during the event was one of being present with her family at her loved one’s bedside and receiving support from others. In the study conducted by

Holm et al. (2012), the researchers identified that partners of patients who received TTM felt guilty if their loved one did not awaken immediately and questioned whether their resuscitative efforts were adequate. Larsson et al. (2013) describe how painful it was for young children to see a parent so ill when receiving TTM; the remaining parent of these children felt a great responsibility toward them during TTM and found it very challenging to witness their sadness and anxiety. No other descriptions of the TTM experience related to the type of relationship to the patient receiving TTM were identified in the literature.

### **Existential Challenges**

The current study revealed how a loved one's cardiac arrest and treatment with TTM provoked existential challenges, such as the meaning, purpose, and value of life. Most participants sought comfort and support from a greater power, such as God, to help them cope with the existential challenges they faced during their loved one's cardiac arrest, resuscitation, and treatment with TTM. Participants described a feeling of peace when they felt God was present in the situation of their loved one's care; God was felt to be present either through the participant consciously handing the care of their loved one over to him, or when a chaplain provided prayers or blessing to the family and patient. Other participants described how specific events and actions appeared to line up correctly during their loved one's event, and this miracle was responsible for the patient's survival. Participants perceived that their loved one's survival was meant to be, and therefore they found comfort in the feeling that events would continue to go in their loved one's favour. Although Löf et al. (2010) note in their study that family members recognize the possibility of the occurrence of miracles, and Larsson et al. (2013) note that religious beliefs can be a source of support for family members during a loved one's treatment with TTM, this constituent has otherwise not been well described in previous studies.

The findings of this study further expand our current understanding of the effect of a greater power on the family members' experience of this phenomenon.

Family members in the current study described feeling a loss of control during their loved one's treatment with TTM and they felt helpless to help their loved one. Participants identified that they worried that their loved one would feel cold and frightened during his or her treatment with TTM. Some participants attempted to put warm blankets on their loved one, but the nurses would remove these blankets so that the target temperature during TTM could be maintained. One participant described how helpless she felt when her son started to awaken and mouthed the words 'help me' to the participant. Being unable to do anything to comfort their loved one or affect the outcome of their loved one's treatment with TTM was perceived as very hard for family members. This finding was noted in the study by Löf et al. (2010) who found that it was stressful for family members to be close to their loved one but not able to influence the outcome of the event.

Many participants expressed how they sought to find the meaning of and understand why this experience was happening to their loved one; prior to this event, their loved one was thought to be a healthy individual. If family members were not informed of the purpose of TTM, they tried to understand why their loved one was receiving TTM because they wondered if they were being needlessly being subjected to the traumatic TTM experience. Some family members identified that there was a perceived unfairness to the situation, and that their loved one did nothing to deserve the cardiac arrest and treatment with TTM. Although Larsson et al. (2013) and Löf et al. (2010) identified that family members found their loved one's treatment with TTM to be difficult and unpleasant, in the study by Holm et al. (2012), partners of patients who received TTM accepted this treatment as a part of their loved one's care. The findings of the

current study expand upon our current understanding of this constituent; to date there has been no discussion in the literature regarding the family members' attempts to find meaning in, or an understanding of, their loved one's cardiac arrest and treatment with TTM.

The experience of a loved one's cardiac arrest and subsequent treatment with TTM resulted in a self-transformation for family members as related to how they perceive and live life after the event. Participants described a new-found understanding of how quickly life can be taken away, and what it might be like to lose a close family member to death. Participants also described how the experience has aged them. They are now more thankful for their family, feel that the experience has brought their family closer, do not take things for granted, and worry less about things that are perceived to be less important. Some participants identified that they feared a recurrence of their loved one's cardiac arrest for months after the initial event. These findings are supported in the literature. Larsson et al. (2013) also found that family members felt that a loved one's cardiac arrest and treatment with TTM changed them and they had recurrent thoughts about death and the meaning of life. Similarly, Holm et al. (2012) described how family members of patients who survived cardiac arrest and treatment with TTM had a persistent fear for their loved one's physical well-being after discharge home. In a study examining the family members' experience 6 months after a loved one's cardiac arrest and treatment with TTM, Wallin et al. (2013) found that these individuals experienced existential thoughts and were more aware of how quickly life could end; as a consequence, their values regarding life changed.

### **Summary**

In this chapter, the findings of the current study were discussed within the context of the current literature regarding the family members' experience of a loved one's cardiac arrest and successful treatment with TTM. The findings of this study add, support, and expand upon our

current understanding of the family members' experience of a loved one's successful treatment with TTM after cardiac arrest. Although there are limitations to this study, there are also implications for practice, theory, and education. These are discussed in the following chapter along with recommendations for future research.



## **CHAPTER 6**

### **Researcher's Journey, Limitations, and Implications**

The purpose of this qualitative study is to explore the family's experience of a loved one's successful treatment with TTM. This phenomenon is poorly understood in the current literature; improved understanding of unfamiliar life experiences can assist nurses to better care for the individuals who experience them (Matua, 2015). Utilizing Giorgi's (2009) phenomenological psychological method, six essential constituents were identified that describe this phenomenon. In this chapter, my journey using Giorgi's methodology will be discussed, implications for nursing practice, theory, and education will be reviewed, and recommendations for future research will be identified.

#### **Researcher's Journey**

A novice researcher conducted this research. As such, limitations exist in my ability to fully understand and apply Giorgi's (2009) phenomenological psychological method to answer the research question. Several strategies were employed to reduce the limitations imposed upon a study conducted by a novice researcher. According to Polit and Beck (2012), a pilot study may be used to test and address any vulnerabilities in the research study, thereby preventing a flawed study. Therefore, a pilot study was conducted where I conducted three interviews, analysed the data, and submitted the digital audio recordings, transcriptions, and steps of the data analysis to my supervisor for feedback on my utilization of Giorgi's method. By doing this, I was then able to adjust my interview approach to gain more depth of data in later interviews, and was also able to enhance my use of bracketing during data collection.

According to Giorgi (2009), bracketing of past knowledge can be very difficult to achieve, but not impossible. Bracketing refers to the researcher not allowing his or her past knowledge to

interfere with being present to the experience as described by the participant; as such, the researcher is acutely aware of his or her past experience as he or she attempts not to let it influence the research (Giorgi, 2009). As a novice researcher, to enhance bracketing during data collection and analysis, I identified my presuppositions that influence me and were foundational to my research. These presuppositions were reviewed prior to conducting each interview so that I was aware of them and consciously set them aside so that I was fully present to the experience of the phenomenon as described by the participant. Additionally, the research questions (see Appendix E) were written out for each interview in my journal so that I could reference them during the interview to direct the participant but not lead them (Giorgi, 2009).

In this study, participants were recruited using a purposive snowball sampling strategy. Every attempt was made to schedule interviews at least several days apart; however, three members of one family wished to attend the interview appointment together, and be interviewed privately, one after the other. Interviewing participants in this manner may have limited my ability to maintain the attitude of phenomenological reduction during all three of these interviews. In an effort to reduce this limitation, additional participants were recruited above the minimum three required according to Giorgi (2009). In total, nine participants were recruited to ensure a depth of data was obtained and data saturation was reached.

### **Limitations**

A limitation within the participant sample also exists for this study. Although it was hoped that there would be an equal number of men and women participants recruited, this was unfortunately not the case. Of the nine participants recruited, only two were men. Markanday, Brennan, Gould, and Pasco (2013) found in their study that men were more likely than women to decline participation in studies. Personal reasons and a disinterest in participating in studies

were the most common reasons identified for why men did not participate in studies (Markanday et al., 2013). This may explain the low number of men recruited for the present study.

Additionally, survivors of cardiac arrest in this population were predominantly men; eight of the nine loved one's were women, and their immediate family members tended to be women. It could be suggested that having more men participate in this study may have provided greater variation in the raw data collected. However, the descriptions obtained from the two men who participated were so detailed and descriptive, that this identified limitation may be very minimal.

### **Implications**

The results of this study shed light on a previously poorly understood phenomenon. The meaning of a family member's lived experience of a loved one's successful treatment with TTM after cardiac arrest is described with the six essential constituents revealed in this study: (a) a loved one's cardiac arrest and treatment with TTM is an extremely traumatic, stressful, and critical event; (b) waiting for the hoped awakening is a daunting, intensely stressful, and emotionally ambivalent experience; (c) need for constant reassurance; (d) lifelessness to life; (e) family relationship and role adoption; and (f) existential challenges. A loved one's cardiac arrest and subsequent treatment with TTM is a phenomenon that is intensely stressful on many dimensions for family members who are on a journey through a complex, frightening, and unknown reality. During this time, family members constantly seek reassurance, and nurses are in an optimal position to support family members who are living this experience. The findings of this study have several implications for the nursing profession. These implications will now be discussed.

## **Implications for Practice**

During data analysis, spirituality was found to be a persistent theme that was described by participants. Some participants expressed this spirituality through their religious beliefs; whereas others described spirituality through a sense of a power beyond themselves or the healthcare team. Canfield et al. (2016) acknowledge that although spirituality is often expressed through an individual's religion, spirituality is not necessarily tied to religion. Despite the obvious importance of spirituality for these family members, it was not noted in the data that nurses provided spiritual care for these individuals. Spiritual care is a necessary component of providing holistic nursing care; belief in a higher power may help family members transcend conscious constraints, experience hope, and seek resolutions during this experience (Canfield et al., 2016). However, nurses often do not feel adequately prepared or comfortable in providing spiritual care to patients, and they fear they may offend the patient when attempting to provide spiritual support (Canfield et al. 2016). Additionally, the heavy demands of nursing care in a busy ICU may preclude the nurse being able to devote the time required to assess and address these needs (Canfield et al., 2016). To meet this currently unmet need for these family members, nurses need to be more comfortable in speaking to family members about their spiritual needs; this comfort could be enhanced through ongoing education or policy changes in institutions where nurses are encouraged and supported to assess the patient's and family members' spiritual needs, which may thereby remove any perceived obstacles.

Several participants identified that not knowing what was going to happen to their loved one and not understanding the process of TTM was very distressing for them. As with the study conducted by Larsson et al. (2013), participants suggested that written material be provided to family members that would describe the purpose and process of TTM. The provision of written

material has numerous benefits for family members of critically ill patients; it enhances verbal information that is provided to the family; it acts as a resource that family members can refer to at any time; and it can provide useful advice about common problems that may be encountered (Paul, Hendry, & Cabrelli, 2004). In critical care units where written information about TTM is not currently available, the addition of this type of information sharing may better support and reassure family members who are experiencing this phenomenon.

Participants in this study described the unique situation where their loved one was required to travel to a larger centre a significant distance away to receive ongoing advanced care. This transfer added a financial, psychological, physical, and emotional burden to family members. For example, the hotel and travel costs combined with being far away from other family members made the experience much more stressful than participants perceived it would have been if they were able to receive all the care they required at the local hospital. Implications for practice in this regard involve nurses advocating for the provision of financial support to these family members, in addition to providing information to them explaining why their loved one has to travel a larger centre for ongoing treatment, what services will be provided there, and what to expect when their treatment at the larger centre has been completed.

The above implications for practice were identified from the essential constituents that were revealed during this phenomenological inquiry. These implications are important in improving the care of these family members. Nevertheless, to realize these practice changes, investment from key stakeholders in the health system and expertise in the practice area are required. The Clinical Nurse Specialist (CNS) functions in the Canadian health system to influence patient care at the bedside and at the organizational level (Canadian Nurses Association [CNA], 2014). The Critical Care CNS provides evidence-based care to patients and

their families and also acts as a consultant and educator to other members of the healthcare team who are caring for these patients (Canadian Association of Critical Care Nurses [CACCN], 2011). Additionally, the Critical Care CNS also facilitates and leads the patients' and families' transitions along the continuum of care (CACCN, 2011). Although there is considerable international data supporting the role of the CNS, the number of CNS roles in Canada has been declining over the last 10 years (Bryant-Lukosius et al., 2010). Implementing the role of the Critical Care CNS in tandem with the noted implications for practice would provide a significant step forward in enhancing the care of family members who are experiencing a loved one's treatment with TTM after cardiac arrest.

### **Implications for Theory**

The results of this study add to the existing nursing knowledge regarding the family member's lived experience of a loved one's successful treatment with TTM after cardiac arrest, an area that has received little attention to date. The descriptions of this phenomenon may be used to either add to existing theory or to build new theories in the field of critical care nursing. According to Meleis (2012), research validates, modifies, negates, or cultivates new theory; theory then provides nurses with a framework to practice more efficiently and effectively. Sinuff, Cook, and Giacomini (2007) note that qualitative research provides a means for nursing to better understand complex phenomena and to explore areas that are poorly understood. These findings can then be used to generate theory about the delivery of care (Sinuff et al., 2007). The results of this study may be used to generate theory to explain how interactions between family members and health care providers in ICU can have a positive or negative effect on the family members' ability to cope during a loved one's critical illness. Knowledge gained from this study could also support theory development around the emotional, psychological, and financial cost borne by

family members when a loved one is transferred to a larger centre a significant distance from home.

Some theories around family support in critical care currently exist. An example is the theory of facilitated sense-making, a middle range theory by Davidson (2010). This theory guides nurses as they support family members of critically ill patients, with the primary goal being prevention of adverse psychological sequel. This is a relatively new theory, and the findings of this study may be utilized to further refine this theory. As more research of this kind is conducted, theories such as facilitated sense-making will continue to evolve, thereby improving nursing practice.

### **Implications for Education**

The findings of this study reveal the importance of spiritual care for family members during their experience of a loved one's treatment with TTM after cardiac arrest. Despite the degree of importance that spirituality has for these individuals, there is little mention in the raw data of nurses assessing this need, or providing care related to this need. This may be because nurses do not feel comfortable or prepared enough to meet the spiritual needs of these family members. Canfield et al. (2016) identified in their study that critical care nurses express a need for further education in regard to addressing the spiritual needs of their patients and families; this could be in the form of formal classes or a reference guide that would assist them in having an awareness of different religions, cultures, or values, as well as how to start a conversation with their patients about spirituality. This need, as identified by the participants in the current study, and in the literature by critical care nurses has implications for nursing education. Education around the spiritual care of patients and their families could be addressed in the formal

preparation of nurses at the university level and also in the workplace through nursing unit educators.

An additional implication for nursing education is increasing the healthcare providers' awareness of the lived experience of family members of patients who are receiving TTM after cardiac arrest. I have practiced in ICU for a number of years and have directly cared for patients who have received TTM as well as their families; some results of the study were unexpected for me. For example, I did not appreciate: (a) the misconceptions that family members experienced while awaiting the awakening; (b) the degree of importance that family members placed on being able to remain close to their loved one; (c) the additional stress that family members endured because of the poor communication skills of healthcare providers; or (d) the burden they bore when travelling to a larger centre a significant distance away. The results of this research could be incorporated into educational programs in critical care areas, thereby providing healthcare providers with insight into the experience of family members during this treatment. With an improved understanding of the family members' experience during a loved one's treatment with TTM, healthcare providers can adjust their delivery of care for these individuals, thereby resulting in increased support for family members and a possible reduction in the incidence of adverse outcomes.

### **Recommendations for Future Research**

The findings of this study add to our current nursing knowledge regarding the family members' experience of a loved one's successful treatment with TTM after cardiac arrest. Although it does answer some questions, it also creates more questions that need to be answered through further research. With increased knowledge about the meaning of this experience for family members, nursing now has to move forward with planning and testing interventions to



better support these individuals during a loved one's treatment with TTM and beyond. A lack of knowing and/or understanding the process of TTM was identified as a significant stressor for participants, and some participants suggested that the provision of written material would be beneficial in reducing this stress. With this knowledge, future research is needed to test the effectiveness of the provision of written information in reducing perceived stress by family members during a loved one's treatment with TTM. This may lead to improved coping by family members and improved outcomes.

Further research is also needed about the families' experience of a loved one's transfer to a larger centre a significant distance away for ongoing care. In the present study, this essential constituent added additional stress to family members who were already experiencing an intensely stressful experience. More could be done to support these family members in this situation, and further research into this will guide the nursing profession.

Lastly, more research is needed into the effectiveness of the implementation of a CNS role in care of this patient and family population. A CNS could support patients and families through direct care, increase healthcare staff capacity through staff facilitation and education, and advocate for policy changes and resource allocation with the goal of improved patient and family experiences and outcomes.

### **Conclusion**

In this chapter, a review of my experience and limitations of the current study were identified and measures taken to reduce these limitations were also discussed. Implications for nursing practice, theory, and education were examined and recommendations for future research made. Although this study identified some common denominators with pre-existing literature, new knowledge was also revealed that was not described in the literature to date and is poorly

understood; more work needs to be done to test interventions that may enable nurses to better care for these individuals. Future research that explores the potential benefits of the provision of written information to family members, interventions to support family members who are required to travel to distant healthcare centres, and implementation of a Critical Care CNS role may reveal strategies that result in better outcomes for these family members.

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## Appendix A

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### Letter of Permission from Health Prince Edward Island

I am a graduate student in the Master of Nursing program at the University of Prince Edward island. A partial requirement for this degree is the completion of a research study. This letter is to explain the purpose of my study, and to seek your approval for my study.

My area of proposed research is the exploration of the families' experience of a loved one's treatment in ICU with targeted temperature management after cardiac arrest. This area has received little attention to date in the literature, and it is thought that families experience significant negative personal health consequences after this experience.

To recruit participants for my study, I would like to put up posters of invitation in various areas in the Queen Elizabeth Hospital (QEH), including the ICU waiting room and the Internal Medicine clinic waiting room. Additionally, because I can't contact potential participants directly, I would request support from Val Hughes (Nurse Manager of ICU) to contact potential participants by phone using a script, to provide them with my number to contact me if they would like to participate. I would also like to ask the Internal Medicine physician group if they would be willing to provide potential participants with the letter of invitation if I was unable to obtain a sample size large enough with my first two stated recruitment strategies. Of course, all of this would be dependent upon your agreement and then approval of both the UPEI and Health PEI REBs.

I ask that you consider my request for your permission to conduct my proposed research as outlined above at the QEH. If you approve me to proceed as outlined above, please indicate by signing next to your name below.

Sincerely,  
Margie Burns  
[meburns@ihis.org](mailto:meburns@ihis.org)  
(902) 894-2143 (work)

Letter of Permission from Health Prince Edward Island

I am a graduate student in the Master of Nursing program at the University of Prince Edward island. A partial requirement for this degree is the completion of a research study. This letter is to explain the purpose of my study, and to seek your approval for my study.

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I ask that you consider my request for your permission to conduct my proposed research as outlined above at the QEH. If you approve me to proceed as outlined above, please indicate by signing next to your name below.

Sincerely,  
Margie Burns  
[meburns@ihis.org](mailto:meburns@ihis.org)  
(902) 894-2143 (work)

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I ask that you consider my request for your permission to conduct my proposed research as outlined above at the QEH. If you approve me to proceed as outlined above, please indicate by signing next to your name below.

Sincerely,  
Marie Burns

#### Letter of Permission from Health Prince Edward Island

I am a graduate student in the Master of Nursing program at the University of Prince Edward island. A partial requirement for this degree is the completion of a research study. This letter is to explain the purpose of my study, and to seek your approval for my study.

My area of proposed research is the exploration of the families' experience of a loved one's treatment in ICU with targeted temperature management after cardiac arrest. This area has received little attention to date in the literature, and it is thought that families experience significant negative personal health consequences after this experience.

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I ask that you consider my request for your permission to conduct my proposed research as outlined above at the QEH. If you approve me to proceed as outlined above, please indicate by signing next to your name below.

Sincerely,  
Margie Burns  
[meburns@ihis.org](mailto:meburns@ihis.org)



## Appendix B

### A Script for Use by the ICU Nurse Manager During Recruitment

The following is a script for the ICU Nurse Manager to use when contacting potential participants by telephone to explain the proposed study and providing the researcher's contact telephone number if they wish to participate.

Margie Burns is a graduate student in the Masters of Nursing program at the University of Prince Edward Island, School of Nursing. She is doing a research study into what it is like for family members when a loved one is in ICU for cooling treatment after he or she has had a cardiac arrest. She is interested in learning about the families' experience during this treatment, so that nurses and other health care providers can better understand what it is like for them. With a better understanding of what it is like for family members, she hopes to find ways to improve our care of families during this time when their loved one is in ICU.

If you agree to be a part of this study, your involvement is completely voluntary. The study involves Margie interviewing family members of patients who had cooling treatment in an ICU. If at any time during the interview you want to stop, you can do so without any consequences. If you want to withdraw partway through the study, any information that has been collected will be destroyed and will not be included in the study report. Margie will use several strategies to keep your participation in the study strictly confidential. She will interview you at a private office at UPEI, code the interview information so that your name is not linked to what you say during the interview, lock up and secure the information you share during the interview, and also use fake names in the study report.

If you want to know more about the study, or wish to participate in the study, you may call Margie at her private office phone: (902) 894-2143. She will be able to give you more information about the study, and answer any questions that you may have before deciding if you wish to participate.

## Appendix C

### Letter of Invitation

#### **The Families' Experience of a Loved One's Targeted Temperature Management after Cardiac Arrest**

**You are invited** to take part in a research project that is taking place at the University of Prince Edward Island (UPEI), School of Nursing. We are doing this study with families of patients who are treated with Targeted Temperature Management (cooling treatment) after cardiac arrest. We want to find out what this experience is like for families, so that nurses and other health care providers can do a better job of looking after families who are going through this experience. Because we want to understand what this experience is like for all members of the family, we would ask you to share this letter with other members of your family that may be interested in taking part in the study. To be able to take part, you must be at least 18 years old, be able to speak and understand English, and be a partner, sibling, child, or parent of someone who has lived after cooling treatment within the last 2 to 24 months.

**Who is doing the research?** The study is being led by Margie Burns, Graduate Student at the UPEI School of Nursing.

**Is taking part in the study voluntary and confidential?** Yes. You can choose whether you want to take part or not. If you decide to take part, you can also choose to leave the study at any time after the study begins. If you decide not to take part, or you choose to leave the study before it finishes, you will be supported to do this. All of the information that you share will be kept confidential within the limits of the law.

**How will the study be done?** If you agree to take part, you will be asked to read and sign a consent form. At this time, you and the researcher will arrange a time and place to meet for an interview. The researcher has a private room at UPEI that can be used. The interview will take between 1 to 2 hours. During the interview, the researcher will ask you to describe what it was like for you during the time around when your loved one had the cooling treatment in the Intensive Care Unit. The interview will be digitally audio recorded, and then typed out for the researcher to look at later.

**What will happen to my information?** At all times, the information that I collect during the study will be secured in a locked drawer at the UPEI School of Nursing. After the study is over, fake names will be used in the study report. If you would like to see the results of the study when it is complete, you can call me and I will mail you a copy of the results.

**Are there risks and benefits to taking part?** There are no known risks associated with taking part in this study. But if you become upset during the interview, I will be able to talk to you about your experience further after the interview if you wish, or I can help you to find someone who can help you. The benefits are that you may help us to better understand how help families when they have a loved one who is getting the cooling treatment after cardiac arrest.

**If you have questions about the study**, please contact Margie Burns at (w) (902) 894-2143, or by email at [meburns@upei.ca](mailto:meburns@upei.ca) or my supervisor, Dr. Gloria McInnis-Perry at (w) 902-628-4301, or by email at [gimcinnis@upei.ca](mailto:gimcinnis@upei.ca). If you have any concerns about how the research was done, please call the UPEI Research Ethics Board at 620-5104 or email [reb@upei.ca](mailto:reb@upei.ca). You can also contact the Health PEI Research Ethics Board at (902) 569-0576 or email [reb@ihis.org](mailto:reb@ihis.org). Please keep this sheet in case you need to look at it later.

Flesch-Kincaid Grade Level 8.2

## Appendix D

### Written Consent Form

#### **The Families' Experience of a Loved One's Targeted Temperature Management after Cardiac Arrest**

If you have read the Letter of Information and would like to take part in this study, please read and sign this consent form.

Here is my contact information and the contact information of my supervisor:

Margie Burns: Master of Nursing Student at UPEI

Phone: (w) (902) 894-2143, email: [meburns@upei.ca](mailto:meburns@upei.ca)

Dr. Gloria McInnis-Perry: Supervisor and Associate Professor, School of Nursing at UPEI

Phone: (w) (902) 628-4301, email: [gjmcinnis@upei.ca](mailto:gjmcinnis@upei.ca)

#### **Purpose of the Study:**

I know that the purpose of this study is to find out what it is like for families when their loved one has the cooling treatment in the Intensive Care Unit after Cardiac Arrest.

I have read and understood:

- ☐ This consent form and that any questions I had were answered by Margie Burns.
- ☐ That this study is being led by Margie Burns at the University of Prince Edward Island.
- ☐ That it is up to me whether I take part in this study.
- ☐ That I will be interviewed by the researcher. The researcher will ask me to describe what it was like for me when my loved one had the cooling treatment after their cardiac arrest.
- ☐ That the information I give will be kept confidential within the limits of the law. To keep my participation in the study confidential, the interview will be done in a private office at UPEI, information will be coded so that my name is not linked to what I say during the interview, this information will be locked up and secured, and fake names will be used in the study report. I understand that anything I say in the interview can be used as a quotation.
- ☐ The study is voluntary. I can choose not to answer any questions, and I can also decide to leave the study at anytime. If I decide not to participate, or to leave the study at any time, there will be no consequences for me. If I want to withdraw partway through the study, any information that has been collected will be destroyed and will not be included in the study report.

- ☐ There are no known risks to taking part in this study. The benefits are that I may help families of patients who are being treated with the cooling treatment.
- ☐ I give permission for the interview to be digitally audio taped.
- ☐ All of the interview information will be kept in a locked drawer at the UPEI School of Nursing. Only the researcher and research team will be able to see and use this information. After 5 years, the information will be destroyed.
- ☐ If I have any questions, I can contact Margie Burns at (w) 894-2143, or by email at [meburns@upei.ca](mailto:meburns@upei.ca), or her supervisor, Dr. Gloria McInnis-Perry at (w) 902-628-4301, or by email at [gjmcinnis@upei.ca](mailto:gjmcinnis@upei.ca). If I have any concerns about how the research was done, I can call the UPEI Research Ethics Board at 620-5104 or email [reb@upei.ca](mailto:reb@upei.ca). I can also contact the Health PEI Research Ethics Board at (902) 569-0576 or email [reb@ihis.org](mailto:reb@ihis.org).
- ☐ I will be given a copy of this consent form to keep.

This study has been explained to me and my questions have been answered to my liking. I have enough information to decide to take part. I agree to take part in **The Families' Experience of a Loved One's Targeted Temperature Management after Cardiac Arrest**.

Name of Participant: \_\_\_\_\_

Participant's Signature: \_\_\_\_\_ Date: \_\_\_\_\_

Researcher's Signature \_\_\_\_\_ Date: \_\_\_\_\_

At home, I would like to be reached by:

☐ Phone home: \_\_\_\_\_ cell: \_\_\_\_\_

☐ Email: \_\_\_\_\_

I would like a copy of the study results mailed to me: ☐ Yes ☐ No

Address:

\_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_  
 \_\_\_\_\_

## Appendix E

### Interview Guide and Demographic Data

1. Can you describe your experience in as much detail as possible when *name* had the cardiac arrest and then was treated with the cooling treatment in ICU?
2. What was it like for you when you first came to visit him or her in ICU?
3. Can you describe what it was like for you when the cooling treatment was finished and you were waiting for *name* to wake up?
4. Describe your experience following the TTM. What was it like? What impact has it had on your life?
5. Is there anything else you would like to share?
6. Other probing questions are:
  - a. Can you tell me more?
  - b. Can you expand on...?
  - c. Help me understand...?
  - d. It was exactly what..?

### Demographic Data

1. Relationship to the patient: \_\_\_\_\_
2. If spouse or partner, length of time of relationship: \_\_\_\_\_
3. Length of time since patient's cardiac arrest: \_\_\_\_\_
4. Participant is: female/ male
5. Age of participant: \_\_\_\_\_
6. Participant was present when the patient had cardiac arrest: Y / N
7. Participant was notified of patient's arrest by: \_\_\_\_\_
8. Participant called Emergency medical Services: Y / N
9. Participant performed CPR on patient: \_\_\_\_\_

## Appendix F

### UPEI Research Ethics Board Approval



550 University Avenue  
Charlottetown  
Prince Edward Island  
Canada C1A 4P3

**To:** Margie Burns  
School of Nursing

**Protocol Number:** REB Ref # 6006754

**Title:** The Families' Experience of a Loved One's Targeted Temperature Management after Cardiac Arrest

**Date Approved:** June 16 2016  
**End Date:** June 15 2017

The above mentioned research proposal has been reviewed and approved by the UPEI Research Ethics Board. Please be advised that the Research Ethics Board currently operates according to the Tri-Council Policy Statement 2: Ethical Conduct for Research Involving Humans (2014) and applicable laws and regulations.

It is your responsibility to ensure that the Ethics Renewal form is forwarded to Research Services prior to the renewal date. The information provided in this form must be current to the time of submission and submitted to Research Services not less than 30 days prior to the anniversary of your approval date. The Ethics Renewal form can be downloaded from the Research Services website (<http://www.upei.ca/research/forms>).

Any proposed changes to the study must also be submitted on the same form to the UPEI Research Ethics Board for approval.

The Research Ethics Board advises that **IF YOU DO NOT** return the completed Ethics Renewal form prior to the date of renewal:

- Your ethics approval will lapse
- You will be required to stop research activity immediately
- You will not be permitted to restart the study until you reapply for and receive approval to undertake the study again.

*Lapse in ethics approval may result in interruption or termination of funding.*

Notwithstanding the approval of the REB, the primary responsibility for the ethical conduct of the investigation remains with you.



## Appendix G

### Health PEI Research Ethics Board Approval

#### Health PEI

PEI Research  
Ethics Board  
16 Garfield Street  
PO Box 2000, Charlottetown  
Prince Edward Island  
Canada C1A 7N8

#### Santé Î.-P.-É.

Comité d'éthique de la  
recherche de l'Î.-P.-É.  
16, rue Garfield  
C.P. 2000, Charlottetown  
Île-du-Prince-Édouard  
Canada C1A 7N8

#### FULL APPROVAL FORM

**Date:** July 6, 2016

**Project Title**                      *The Families' Experience of a Loved One's Targeted Temperature Management After Cardiac Arrest*

**Principal Investigator:**      Margie Burns

#### Documents reviewed:

- Completed Submission Checklist (Dated June 28, 2016)
- Coverletter from Margie Burns (Dated June 28, 2016)
- Research Protocol (Not Dated)
- Appendix A: Letters of Permission from Health PEI
  - Val Hughes, Nurse Manager, ICU/PCU, QEH (Dated May 9, 2016)
  - Marion Dowling, Director of Nursing, QEH (Dated May 9, 2016)
  - Jamie MacDonald, Chief Administrative Office, QEH and Community Hospitals East (Dated May 9, 2016)
  - Pam Trainer, Executive Director, Acute Care, Mental Health and Addictions (Dated May 6, 2016)
  - Dr. Pat Bergin (Dated May 9, 2016)
  - Dr. Lenley Adams (Dated May 9, 2016)
  - Dr. Paul Seviour (Dated May 9, 2016)
- Appendix B: A Script for Use by ICU Nurse Manager During Recruitment (Not Dated)
- Appendix C: Letter of Invitation (Not Dated)
- Appendix D: A Script for Use by Internal Medicine Clinic Administration Assistant During Recruitment (Not Dated)
- Appendix E: Written Consent Form (Not Dated)
- Appendix F: Interview Guide and Demographic Data (Not Dated)
- Appendix G: Projected Budget for Proposed Study (Not Dated)
- CV of Margie Burns (Not Dated)
- Association of Registered Nurses of Prince Edward Island Membership License and Receipt 2016 for Margaret Elizabeth Burns (Valid to October 31, 2016)
- Approval letter from the UPEI Research Ethics Board (Dated June 16, 2016)
- Confirmation of Supervisor's Review Form (Dated June 28, 2016)
- TCPS 2: CORE Certificate of Completion (Dated September 10, 2015)

Full approval has been granted for the above noted study. This study was reviewed according to ICH GCP Guidelines and will require an annual report and request for re-approval to be in place prior to July 6, 2017.

Tel/Tél.: 902 569 0576

[www.healthpei.ca](http://www.healthpei.ca)

Fax/Télé.: 902 368 4969

ONE ISLAND FUTURE, ONE ISLAND HEALTH SYSTEM



UN AVENIR UNIQUE, UN SYSTÈME DE SANTÉ UNIQUE

Notification of closure is required once the study is completed or terminates early. The “Continuing Review Reporting Requirements”; the “Reporting Study Closure and/or Early Termination”; and the “Request for Annual Approval” forms are attached.

*ATTESTATION:* This Research Ethics Board complies with Division 5 of the Food and Drug Regulations, the ICH Harmonized Tripartite Guidelines Good Clinical Practice, and the Tri-